

**“How do I need to be  
in order to be with  
you?” – Building  
partnerships that  
enrich lives**

Dr Sheridan Forster



- Who are people with profound intellectual and multiple disabilities & what is interaction with them?
- What does this mean to you and me?
- What do we need to do now?



# Let's walk into a room

- Walk into the room

- What do you think?

- What do you do?

- Do you approach the person?

- Do you decide to try to interact with the person?

- And the person doesn't appear to respond...
- What do you do?

- Do you touch their hand?
- Do you make their cooing sound and look for their response?

- A person who might be their staff member walks back into the room
- What do they do?
- What do you feel?
- What do you do?

- Why do we do what we do?
- Have you ever done something like this?
- Why would “the community” do what they do?

- How do we build partnerships if this is the sort of foundation that exists?

# Each week in the hydro pool...

- Now as a patient, I experience this each week:
  - Do I approach?
  - Do I engage?
  - Do I change what I do?
  - Do I need permission from the staff?
  - What do they think of what I'm doing?
  - Am I a pseudo clinician or a "member of the community"?
  - What are the other people in the pool thinking?
  - Would this change what they do?

# Who are people with Profound Intellectual & Multiple Disabilities?

- “Children and adults with PMLD have more than one disability, the most significant of which is a profound intellectual disability. These individuals all have great difficulty communicating, often requiring those who know them well to interpret their responses and intent. They frequently have other, additional disabling conditions which may include for example:
  - Physical disabilities
  - Sensory impairments
  - Sensory processing difficulties
  - Complex health needs
  - ‘Coping behaviours’
  - Mental health difficulties”
    - (Doukas, Fergusson, Fullerton, & Grace, 2017)(Core and Essential Services Standards, 2017)

# But what is profound intellectual disability?

- Profound cognitive impairments
  - Concentration – single line, short term
  - Memory – poor short term memory – long term memory
  - Problem solving – using the same way to solve problems
- DSM-5 – dependent for all aspects of daily care, comm skills quite limited (specificity from severe?)
- AAID – Pervasive support – “most intense levels of support”
- It is not a values statement

# How many people are we talking about?

- Emerson – PID 0.05/1000 (Emerson, 2009)
- Bray – PID 0.08/1000 (Bray, 2003)
- Scotland ([The Keys to Life, 2013](#)) – 2,600-3,000 people
  - NZ – ~2,400
  - Australia - ~12,500

- [PIMD IASSID special interest research group](#)
- Profound Multiple Learning Disabilities (PMLD) – UK recognised group for many years
  - [Mencap PMLD practice leaders](#)
  - University courses ([Birmingham](#) and Manchester)
  - [PAMIS](#) advocacy and White Tops centre
  - [Changing Places Campaign](#) (also see [Changing Places Australia](#))
  - [PMLD Link](#) magazine
  - [Raising Our Sights – Mansell](#) and [videos](#)
  - [Supporting people with profound and multiple learning disabilities – Core & essential service standards](#)
  - [Inclusive Communication](#) - RCLST
- Australia – some recognition by practitioners and researchers, some informal support groups looking at specific issues for people with SPID
- You can not lobby for a group that you can not name... (Forster, 2010)

- Intellectual disability as a single group
- Severe and profound intellectual disability as a single group
  - SPID (problem when groups differ significantly (Forster, Gray, Taffe, Einfeld, & Tonge, 2011))
  - DM-ID2 examines diagnosis according to mild-mod and sev-prof
- Poor group identification
  - Age
  - Intervention – e.g., Rett syndrome
- Steady flow of research from Netherlands, Belgium, Germany, UK, and Australia

# What is interaction with people with PIMD?

- Is it talking to the person like you do anyone else?
- Is it using pictures for every time you talk to the person?
- Is it about the number of words we use and they understand?
- Is it unachievable for people with PIMD – they don't communicate?
- Is it just single expressions of like and dislike?
- Is it you telling them what's happening?
- Is it a belief that they understand everything that's being said to them - they are just locked into their body?
- Is it something quite different?

**Used with permission at the  
conference only**

- Removed for public distribution
- Contained video recording of Sheridan interacting with a man with multiple disabilities. Video shows interaction through touch, movement, sounds, proximity, proposing and accepting different movements and play

- Communication for people with PIMD was:
  - Personal communication dictionary
  - Touch cues
  - A chat book
  - (Using a aided language display...)
  - Object symbol program
    - But, I returned to its origins
      - 1980s CRS van Dirck (McLarty, 1997)
        - Attachment, security, co-active movement
        - Thus began my eyes towards Western European Deafblind approaches

# Intensive Interaction: Fundamentals of Communication

- Enjoying being with another person
  - Developing the ability to attend to that person
  - Concentration and attention span
  - Learning to do sequences of activity with a person
  - Taking turns in exchanges of behaviour
  - Sharing personal space
  - Using and understanding eye contacts
  - Using and understanding facial expressions
  - Using and understanding physical contacts
  - Using and understanding other non-verbal communications
  - Vocalising and using vocalisations meaningfully (incl speech)
  - Learning to regulate and control arousal levels
  - Lots and lots of emotional elements
- (Hewett & Nind, 1998; Nind & Hewett, 1994, 2001, 2005)

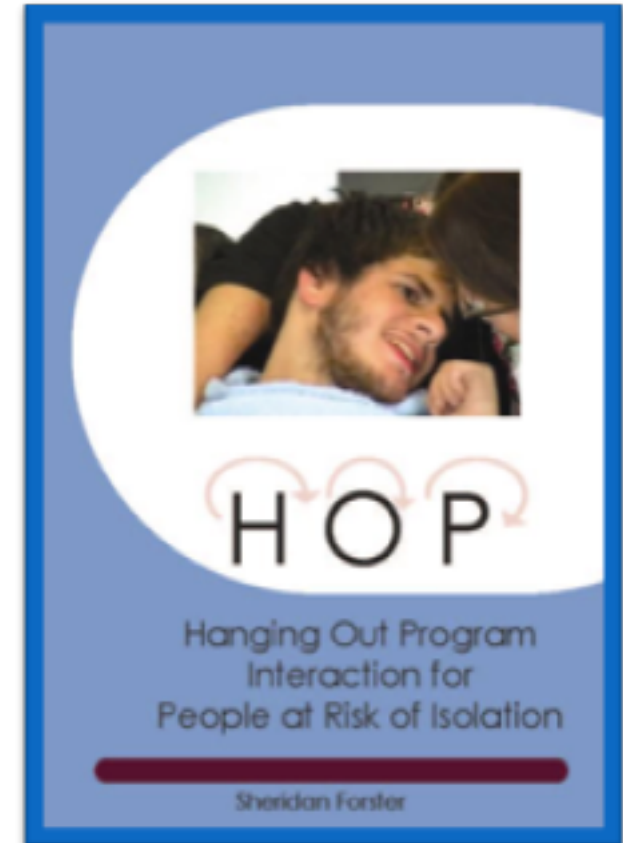


- Phenomenological approach
- 3 disability support workers, semi-structured interview discussing
  - what it was like interacting with Daphena
  - how they had learnt to communicate with her
  - what was useful or not useful in learning to communicate
  - how their workplace policy and common practices influenced interacting with
- Themes:
  - Learning through experience
  - Age appropriateness?
  - An emotional relationship
  - Communication roles
  - Believing in understanding
  - Interaction in competition
  - A hidden culture of communication
- (Forster & Iacono, 2008)

- The performance of behaviours that express the quality of feeling of shared affect state without imitating the exact behavioural expression of the inner state (Stern, 1985)
  - Behavioural modality same or different
  - Clear affective emphasis must be present (Jonsson & Clinton, 2006; Jonsson et al., 2001)
- Enables a focus on all affects – not just like

- The majority of the DSWs used affect attunement
- The attuned response usually matched the intensity of the behaviour of the adult with PIMD
- The incidents were quick, averaging 2.3 seconds
- While the person with PIMD usually used posture, facial expression and vocal behaviours as the eliciting behaviour, the DSWs usually responded with speech accompanied by posture and facial expression
- The behaviour used by the adult with PIMD was frequently a motor or attention signalling behaviour
- Implications: The behaviours which DSWs attune are often idiosyncratic and fleeting. However, these brief moments of connection may be very important to the quality of interaction and feelings of connection.
- (Forster & Iacono, 2014)

- Going into a day service and Chris always being alone
- Interviewing support workers about interacting with people with PIMD
  - you have the nice time when the work is finished
- Paradigm shift
  - Not to focus on the skills of interaction, but to focus on the culture and the permission to interact and celebrate interactions
- [\(Forster, 2008\)](#)



# HOP: An attitude and approach

- Approach
  - To spend 10 minutes with a person giving them total attention in the interaction
  - To briefly write down what happened in the interaction
- Attitude
  - All people benefit from interactions
  - All people want to connect with another person—but this is hard for some people
  - Enjoying the company of another person is one of the most fundamental communication skills that needs to be supported
  - Part of our role in supporting people with multiple disabilities is engaging with them
  - Engagement must be meaningful to the person with a disability and the interaction partner
  - If the person can not understand the “language” of the support person, then the support person must adapt their language. It should match the language of the person with a disability and what is meaningful to them
  - Communicating with people with multiple disabilities is everyone’s job, including managers, all staff, and even other service users!

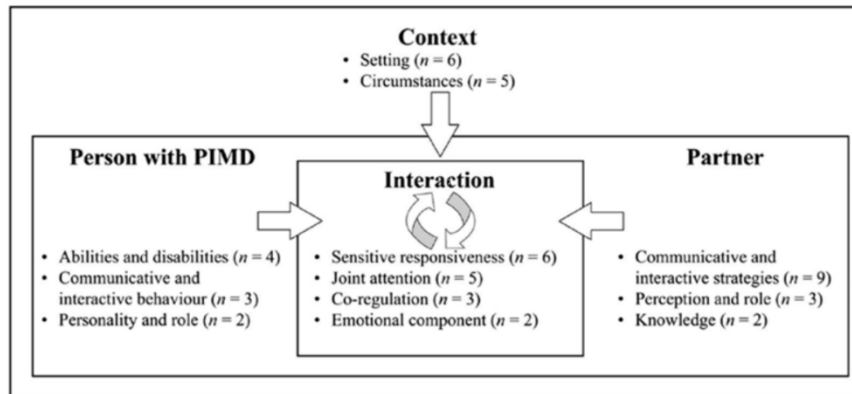


Figure 1. Explanatory model of the interaction between persons with PIMD and their partners. The number of studies that informed each interaction element is indicated.

## **Sensitive responsiveness**

the way partners perceive each other signals accurately and correspondingly respond to each other

## **Joint attention**

the sharing of a focus between two partners

## **Co-regulation**

the relationship between the behaviours of two partners, the interaction synchrony, the mutual coordination, and the moulding of communication in flexible ways

## **Emotional component**

mutual feelings of contentment, appreciation and joy; sympathy, warmth, and closeness or an emotional bond

“Accentuating the positive”  
Understanding what works in a dyad, and how to do it more



## Principles of Attuned Interactions & Guidance



<b>Being Attentive</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Looking interested with friendly posture</li> <li><input type="checkbox"/> Giving time and space for other</li> <li><input type="checkbox"/> Turning towards</li> <li><input type="checkbox"/> Wondering about what they are doing, thinking or feeling</li> <li><input type="checkbox"/> Enjoying watching the other</li> </ul>
<b>Encouraging Initiatives</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Waiting</li> <li><input type="checkbox"/> Listening actively</li> <li><input type="checkbox"/> Showing emotional warmth through intonation</li> <li><input type="checkbox"/> Naming positively what you see, think or feel</li> <li><input type="checkbox"/> Using friendly and/or playful intonation as appropriate</li> <li><input type="checkbox"/> Saying what you are doing</li> <li><input type="checkbox"/> Looking for initiatives</li> </ul>
<b>Receiving Initiatives</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Showing you have heard, noticed the other's initiative</li> <li><input type="checkbox"/> Receiving with body language</li> <li><input type="checkbox"/> Being friendly and/or playful as appropriate</li> <li><input type="checkbox"/> Returning eye-contact, smiling, nodding in response</li> <li><input type="checkbox"/> Receiving what the other is saying or doing with words</li> <li><input type="checkbox"/> Repeating/using the other's words or phrases</li> <li><input type="checkbox"/> Receiving and then responding</li> </ul>
<b>Developing Attuned Interactions</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Checking the other is understanding you</li> <li><input type="checkbox"/> Waiting attentively for your turn</li> <li><input type="checkbox"/> Having fun</li> <li><input type="checkbox"/> Giving a second (and further) turn on same topic</li> <li><input type="checkbox"/> Giving and taking short turns</li> <li><input type="checkbox"/> Contributing to interaction / activity equally</li> <li><input type="checkbox"/> Co-operating - helping each other</li> </ul>
<b>Guiding</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Scaffolding</li> <li><input type="checkbox"/> Extending, building on the other's response</li> <li><input type="checkbox"/> Judging the amount of support required and adjusting</li> <li><input type="checkbox"/> Giving information when needed</li> <li><input type="checkbox"/> Providing help when needed</li> <li><input type="checkbox"/> Offering choices that the other can understand</li> <li><input type="checkbox"/> Making suggestions that the other can follow</li> </ul>
<b>Deepening Discussion</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Supporting goal-setting</li> <li><input type="checkbox"/> Sharing viewpoints</li> <li><input type="checkbox"/> Collaborative discussion and problem-solving</li> <li><input type="checkbox"/> Naming difference of opinion</li> <li><input type="checkbox"/> Investigating the intentions behind words</li> <li><input type="checkbox"/> Naming contradictions/conflicts (real or potential)</li> <li><input type="checkbox"/> Reaching new shared understandings</li> <li><input type="checkbox"/> Managing conflict (back to being attentive and receiving initiatives with the aim of restoring attuned interactions)</li> </ul>

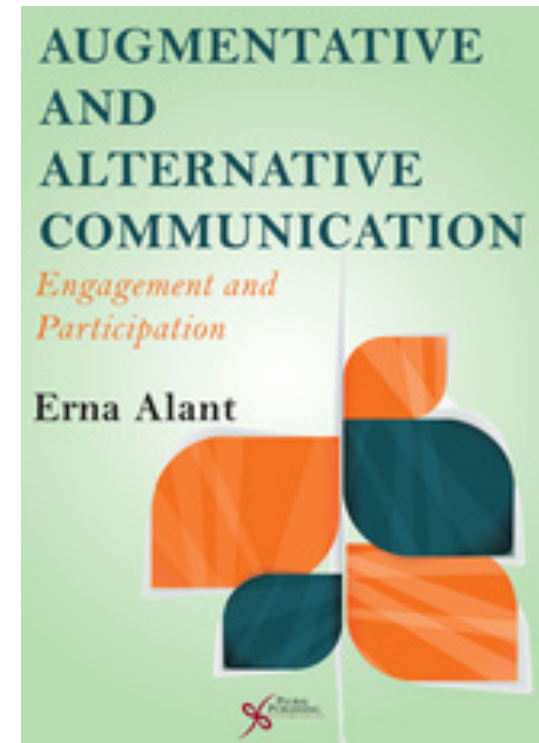
## Principles of Attunement



- Series: 2006.  
Communication and congenital deafblindness. I-4. St. Michielsgestel, The Netherlands: VCDBF/Viataal.
- Building narratives across moves in interaction
- The impression of the expression



- 2017 in a book about augmentative and alternative communication raised a concern about the type of communication that is being taught
- Communication is about meaning making with another person
- Participation
  - Doing with
- Engagement
  - awareness of self and other - intersubjectivity
  - Being with



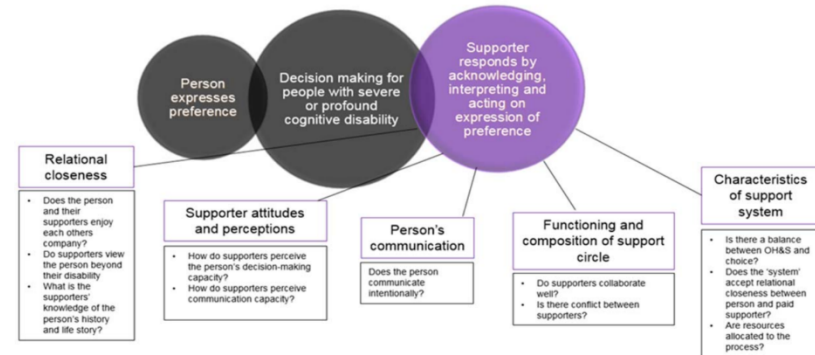
# Special Books for Special Kids – Chris & Marianna – The Missing Ingredient

[https://www.facebook.com/specialbooksbyspecialkids/  
videos/941087115993269/](https://www.facebook.com/specialbooksbyspecialkids/videos/941087115993269/)

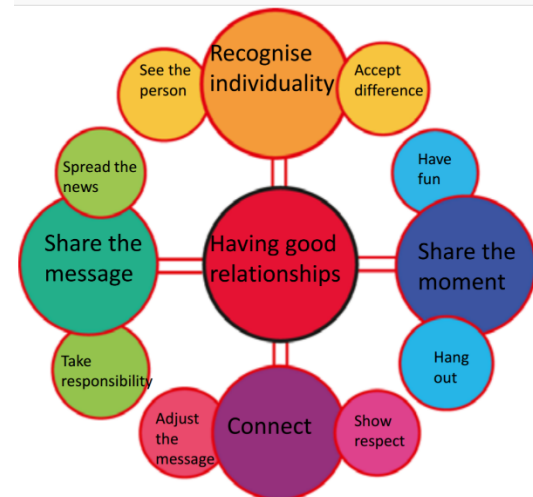
# Without great quality interactions with people with PIMD...

- The person has a reduced quality of life (Petry, Maes, & Vlaskamp, 2009)
- The person can not participate in supported decision making (Watson, Wilson, & Hagiliassis, 2013, 2017)
- The person's opportunities for relationships are reduced (Johnson, Douglas, Bigby, & Iacono, 2010, 2012a, 2012b)
- The person will have greater health problems

A model of decision making support for people with severe or profound cognitive disability



(Watson, 2016)



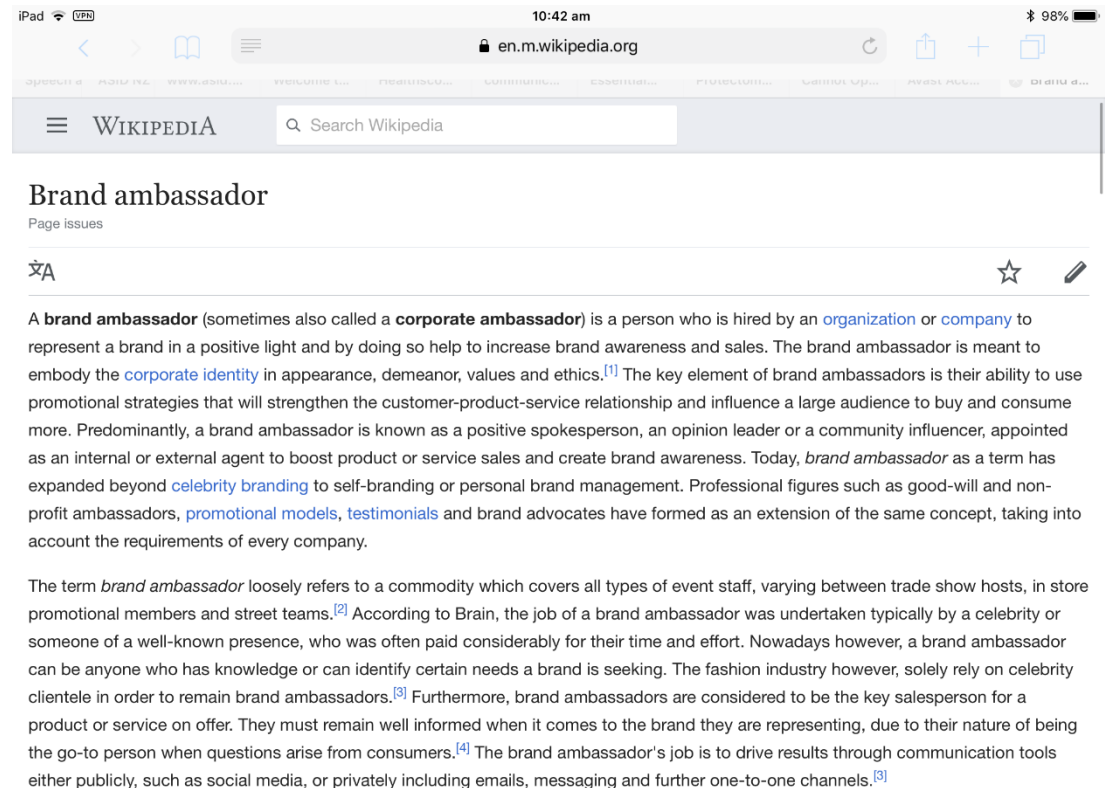
# What does interaction with people with PIMD mean to you?

- Researcher
- Clinician
- Service manager
- Disability support professional
- Family member
- A person with an intellectual disability
- A random person in the community

# What we need to do now to build these partnerships?

- Ambassadors for engagement
- Interpreters
- Models of engagement
- Scientist/researchers
- Philosophers and ethicists

- 1 An accredited diplomat sent by a state as its permanent representative in a foreign country.
- 1.1 A representative or promoter of a specified activity. *'he is a good ambassador for the industry'*
- Origin Late Middle English: from French ambassadeur, from Italian ambasciatore, based on Latin ambactus 'servant'.



Brand ambassador




Page issues

✎

A **brand ambassador** (sometimes also called a **corporate ambassador**) is a person who is hired by an [organization](#) or [company](#) to represent a brand in a positive light and by doing so help to increase brand awareness and sales. The brand ambassador is meant to embody the [corporate identity](#) in appearance, demeanor, values and ethics.<sup>[1]</sup> The key element of brand ambassadors is their ability to use promotional strategies that will strengthen the customer-product-service relationship and influence a large audience to buy and consume more. Predominantly, a brand ambassador is known as a positive spokesperson, an opinion leader or a community influencer, appointed as an internal or external agent to boost product or service sales and create brand awareness. Today, *brand ambassador* as a term has expanded beyond [celebrity branding](#) to self-branding or personal brand management. Professional figures such as good-will and non-profit ambassadors, [promotional models](#), [testimonials](#) and brand advocates have formed as an extension of the same concept, taking into account the requirements of every company.

The term *brand ambassador* loosely refers to a commodity which covers all types of event staff, varying between trade show hosts, in store promotional members and street teams.<sup>[2]</sup> According to Brain, the job of a brand ambassador was undertaken typically by a celebrity or someone of a well-known presence, who was often paid considerably for their time and effort. Nowadays however, a brand ambassador can be anyone who has knowledge or can identify certain needs a brand is seeking. The fashion industry however, solely rely on celebrity clientele in order to remain brand ambassadors.<sup>[3]</sup> Furthermore, brand ambassadors are considered to be the key salesperson for a product or service on offer. They must remain well informed when it comes to the brand they are representing, due to their nature of being the go-to person when questions arise from consumers.<sup>[4]</sup> The brand ambassador's job is to drive results through communication tools either publicly, such as social media, or privately including emails, messaging and further one-to-one channels.<sup>[3]</sup>

- Showing the dialogue that can occur through photos, videos, descriptions
- Drawing recommendations from interactions
- Considering whether our current dominant model of communicative intentionality serves to enhance dialogicality or undermine it

Time	Still shot	Observation	Analysis
06		We began the interaction with me sitting very close to X.	In approaching him, I looked at whether he would respond (by looking or listening) at 2m, 1m, and given the limited response I sat within his contact with my knee touching his and face close
07		X tapped his foot.	I tap his knee trying to show him that I noticed that he tapped his foot (I am using his focus to try to get his interest in me)
08		X looks at me briefly.	I've noted that X's responses are very small. I see this as a good outcome – showing interest in another person is an important socio-communicative skill

# Deeply understand our current interactions

- Deeply understanding
  - 1<sup>st</sup> person knowledge
  - 2<sup>nd</sup> person knowledge
  - 3<sup>rd</sup> person knowledge
  - (Reddy, 2008)
- Rich descriptions of interaction should be part of all communication assessments
  - Communication transcripts
  - Subtilting interactions



<https://www.youtube.com/watch?v=k88BSQJUGaM>

# RCSLT – Five Communication Standards

1. There is a detailed description of how best to communicate with individuals.
2. Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.
3. Staff value and use competently the best approaches to communication with each individual they support.
4. Services create opportunities, relationships and environments that make individuals want to communicate.
5. Individuals are supported to understand and express their needs in relation to their health and wellbeing.



- Interpreters to help the person with a disability understand as best possible
- Interpreters to help the “community member” understand the person
  - Consider the feelings of the person
  - Positively guide them
  - Be aware of signals which might discourage
- Social interpreters

Dreenagh Lyle – 6-7 PMLD-LINK 2018

Reflecting on the Core and Essential Standards  
I am strongly committed to supporting our team. In my professional work it has always concerned me that there is such a lack of reflective practice generally in the social care sector. Workers feel they have to cope but are often not supported to share their thoughts. Spending all day with someone who uses the word ‘salad’ as a sensory tool could be fulfilling and rewarding, but could equally be extremely stressful. I came home one day to be told , ‘she’s been saying “I want to kill you” all day ... But she doesn’t mean it ... does she?’ The way this worker asked, I could sense, at some level, she really wasn’t sure. Ten minutes spent discussing this allays concerns and helps the worker feel confident in their support style . The feel empowered to speak up instead of just ‘get on with it’.

- Being informed by current research
  - Disability research
  - Infant research
- Adding our own stories to research
- Reflective practitioners

- We need to demonstrate high quality interaction

- What is the right thing to do here?
- For the good of the person or the good of society
  - Compromising a persons connection to make things “look normal”
- Challenge concepts like age appropriateness which may operate as barriers in individuals lives (Forster, 2010)
- Seriously examine to need for close relationships with staff and others
- Examining place of people with PIMD in context of “presume competence” and ableism
- “First person” writing
  - Dangers of misrepresentation

# Let's return to that room...

# The Procter Sisters

- <https://youtu.be/NKzaUuixlQ8?t=12m30s>

1 min

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