

IPWSO 2019 Conference

In November last year I was privileged to attend the International PWS conference in Cuba. The conference was four full days (two science/carer-focused days and two parent days) and I attended all of them. As you can imagine, some of the talks were more relevant/useful to our situation than others. There was a LOT of information to digest, so on the plane on the way home I summarised some of the more important key points that I wanted to implement for our daughter Josie (age 4). Here is a summary of those key points.

- 1) Emotional development and empathy training – An important area to be intentional about at any age. Some key points for us were to teach emotions including secondary ones (embarrassment, pride, shame), to talk about our own and others feelings, and to discuss the precedent to different emotions (ie, why someone is feeling what they're feeling). Encouraging the child to notice others, what they are feeling and why.
- 2) Social skills training and lots of regular social experiences (groups) – Play groups, dance class, daycare, anything that gets her around others. Explicit teaching of social skills is needed as our children do not tend to learn these through observation.
- 3) Intentional active play and exercise, recommended was 5-7 times per week (both aerobic and strengthening) – Instead of relying on this to happen naturally, build regular times for this into their routine through activities (swimming, dance) and daily routines (eg, walking/biking to daycare, playground time)
- 4) Visual learning – Verbal conversations have limited use as children will often miss parts and fill the gaps with their imagination. All classroom activities need to have a visual component.
- 5) Intentional flexibility to develop task-switching and ability to cope with change – Flexible (structured) environments at a young age seem to help with change-related difficulties long term.
- 6) Behaviour management – A key strategy to use is low expressed emotion (and low attention) when dealing with problem behaviours. Go to <https://pittsburghpartnership.com/educational.html> to download Dr Gourash's handout on "essential communication skills for families" which was the talk she gave at the conference. This page also has a range of other useful downloadable resources on food security, behaviour management and mental health in PWS.

If any of the above points is of particular interest for you, please feel free to email me (tonyandhayley@gmail.com) and I'll send you what information I can around it. Unfortunately most of the conference talks were very fast-paced (particularly the science days) and they did not provide handouts, so my notes and powerpoint slide photos are not exhaustive. However I am more than happy to share what I do have on any particular topics of interest.