



POSITIVE AUTISTIC / PDA IDENTITY

A FOCUS ON CHILDREN & YOUNG PEOPLE

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Identity: Autism

- Some things I have heard/read from parents/carers...

"I don't want them to be defined by their autism!"

"There is so much more to them than just autism!"

"I haven't yet told them they have autism because I don't want it to become their whole identity."

"Why do they need a label?"

"I am worried it will negatively affect their mental health."

- Notice the detachment of autism from the individual in the use of language – what might that suggest about the parent/carers view of autism?
- Notice the adult's perceived ownership of the child/YP's identity & consider how that would remove autonomy for our PDA'ers.
- But all these parents come from a place of love & wanting to do the right thing...





Developing Identity: Research

- "more dissatisfaction with autistic personal identity predicted lower self-esteem, and **more autism pride predicted higher self-esteem**" (Cordon et al., 2021);
- having a stronger sense of autistic social identity was associated with more positive self-esteem, and noted that **greater autistic social identification could link to better mental health via increased self-esteem** (Cooper et al., 2017);
- "...there is evidence that some autistic people prefer to see autism as integral to their identity, and that having a **positive sense of autism identity has benefits for mental health.**" (Farahar, 2021).



Developing Identity: Disclosure

Telling them they are Autistic / PDA'er: When & How

- "...autistic adolescents whose parents voluntarily disclosed their child's autism diagnosis to them were better able to define autism and more often used neurodiversity-aligned language when doing so as compared to adolescents whose parents told them about their autism involuntarily or not at all... Our findings also provide some preliminary evidence that open discussions about autism may foster positive identity development more generally (Ricco et al., 2021);
- "The sooner your child knows she is autistic the better... Understanding what it means to be autistic... is to provide a child with the opportunities to genuinely have an understanding of self. Without knowledge as to who he is, what an intrinsic component of his very being means, is to gravely misjudge self and potential damage to self-esteem and wellbeing'. (Beardon, *What Works For Autistic Children*);
- "How you talk to your child about autism is going to shape how they think about autism. It informs their whole identity and idea of self-worth... learning more about autism and developing a sense of autistic pride is only going to help them... If you don't give them the words, the explanation, for what's going on, they are going to come up with their own, and they are likely to be negative... Give your child the self-awareness to be their own advocate" (Wassell, *Nurturing Young Autistic Young Person*);
- "Autistic adolescents whose parents talked to them openly about being autistic tended to describe themselves and autism more positively than teens whose parents did not tell them or did so involuntarily" (Ricco et al., 2021);
- If awaiting identification: Consider telling them beforehand! They will already know they are different, depending on lived experience they may already have some knowledge (correct or otherwise) on autism / PDA, you could look together at learning & see if they relate to it. "Be casual and matter of fact" (Wassell, *Nurturing Young Autistic Young Person*).

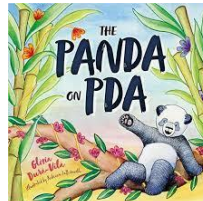
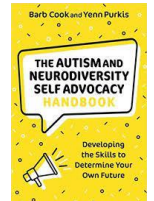
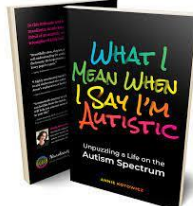
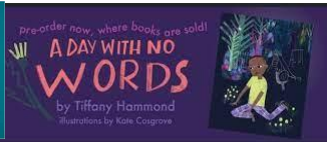
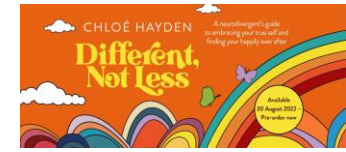
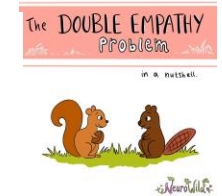
Exploring Identity: How

Learning about autism / PDA: What? How?

- Neurodiversity paradigm & movement – culture
- Models of disability: medical, social, social-relational;
- Neurocognition, sensory systems;
- The problematic nature of the Theory of Mind hypothesis that tends to dominate social discourse on autism (e.g. Autistic people lack empathy);
- Double Empathy Problem;
- Monotropism;
- PDA profile specific;
- What their own needs are;
 - "Self-understanding is often the first step toward seeking the support needed to fully experience society and life. By recognizing oneself as autistic and as having autistic needs, one can connect with communities that can help guide one towards ways of fulfilling these needs." (Botha & Gillespie-Lynch., 2022)
- What's not autism (knowledge or co-occurring conditions/experiences)
- How & when to self-advocate etc... etc...

- Suggest **not**: 'Superpowers', 'different abilities', being entirely positive all the time – there is space for neutrality & acknowledging difficulties (link to models of disability), just a 'one time' thing...

Some potential child/YP friendly sources...





Exploring Identity: How

Overcoming their own barriers: Looking beyond the areas just considered...

- Meet them where they are, it can't be forced or rushed – if it's not in their flow then respect that;
- Keep lines of communication open, any question is ok! Any way of asking a question is ok;
- All feelings are valid feelings - hold space for them to express whatever they feel & consider strategies that may explore misconceptions at another time;
- Understanding: Important to presume competence & consider personalising approach to suit developmental stage rather than age;
- Strewing! Watch / read something nearby... Leaving things lying around... Having discussion that can be overheard...
- A way in might be through role-play / their interest (as long as respectfully allowing them to lead & not 'using' this for your own motive);
- If you are confident in your knowledge of autism/PDA then you may casually comment on everyday aspects of their lived experience in a neutral / positive way. This might both on difference & similarity;
- Same for difference & diversity in the world – model celebration of this (emphasis on difference between Autistic people too!);
- Consider access to professionals (more on this in a moment).



Exploring Identity: How

Overcoming barriers with wider society & individuals around them:

- May be quite similar to approaches for your child!
- Hard decisions about contact/interaction;
- Be their advocate – put barriers in place when needed, openly challenge other people's incorrect perceptions, mistreatment.
 - *Note on privilege – fully appreciate there are huge issues here, not everyone can home educate, not everyone can get by without the help of a family member who may be problematic...*
- Remember the protective barrier that having a strong, positive Autistic identity can have - we cannot control or protect them from everything but we can support the their emerging identity.



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Recommended Reads:

