

PATHOLOGICAL DEMAND AVOIDANCE: HYPE OR HARD GRAFT?

**TEACHERS: MICHELLE AND MICHELINE
AND HEALTH EDUCATION INTERFACE MENTAL
HEALTH STAFF**

JENNY AND KERRY SA HEALTH

**ACKNOWLEDGMENTS TO DPP DfE, SERVICE USERS AND
FAMILY**



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SA Health

**ON THE MENU FOR TODAY: YUMMY STUFF.....
MAIN FILLING (WHAT THE TEACHERS DID) BETWEEN THE
TOP SLICE (“PDA”) AND BOTTOM SLICE (HEI SERVICE)**



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PDA

PATHOLOGICAL DEMAND AVOIDANCE

**A SUBSET OF INDIVIDUALS WITH
AUTISM SPECTRUM DISORDER (ASD)
DISPLAYING OBSESSIVE AVOIDANCE OF
EVERYDAY DEMANDS AND REQUESTS,
STRATEGIC OR 'SOCIALLY
MANIPULATIVE' BEHAVIOUR AND
SUDDEN CHANGES IN MOOD**



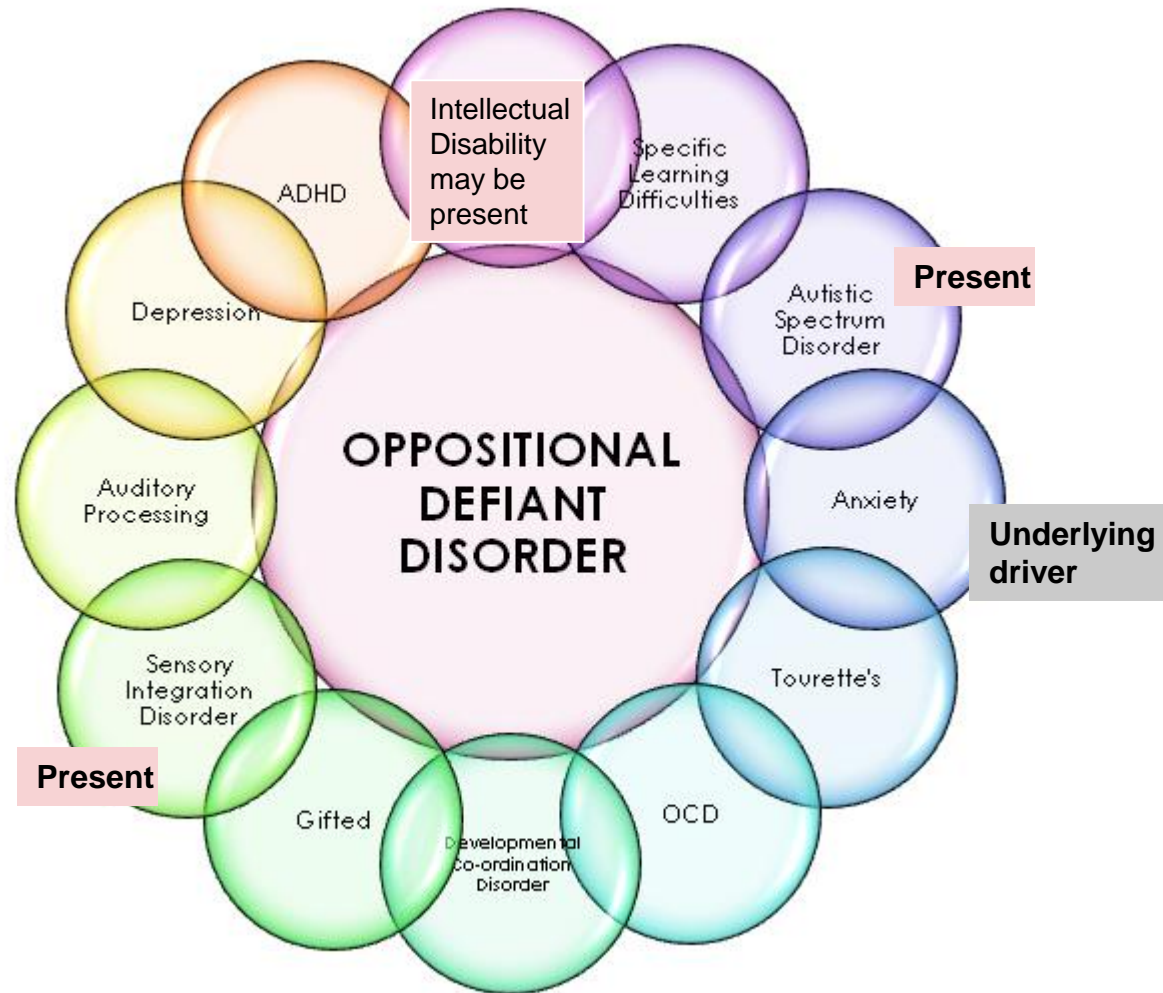
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SCHOOLS ARE WHERE THIS PROFILE BECOMES PARTICULARLY EVIDENT.....



“AVOIDANT, OPPOSITIONAL OR DEFIANT”? PSYCHIATRIC PERSPECTIVE



ANXIETY UNDERLIES PDA



SURVEY OF 26 STUDENTS WITH IDENTIFIED PDA AND THEIR PARENTS (O'NIONS ET AL 2017)

Avoidance behaviours could be described as 'strategic' rather than 'manipulative'

Parents perceived that a range of factors played a role in triggering extreme behaviour, including a

negative emotional response to perceived pressure

sensory sensitivities

phobias

anxiety about the unknown

perception of time pressure

perception of others expectations



PDA SURVEY *O'NIONS ET AL* 2017

More than a third of parents (10/26) reported that their child had been a placid, easy baby, but

Just over a quarter (8/26) had reportedly been difficult and demanding

Nearly half of parents (11/26) noted that extreme stubbornness and refusal to comply was evident at nursery

Although was not always considered 'beyond the norm'



PDA *O'NIONS ET AL 2017*

CONTINUED

More than three quarters (22/26) displayed obsessive or controlling behaviour towards family members or favoured individuals

Over three-quarters of parents (21/26) reported that their child was bossy and controlling towards peers

e.g. 'His 'friends' are those who like his interests and abide by his rules'



PDA *O'NIONS ET AL 2017*

CONTINUED

Nearly two-thirds (16/26) of children reportedly engaged in fantasy activities

(e.g. making up stories/scenarios) which were frequently elaborations of things that they had observed

Several insisted that family members take on specific roles

Nearly half of parents (12/26) reported that their child seemed to take engagement with fantasy 'too far', either persisting in adopting a role after play had ended, or confusing what had happened in play with reality

Just over a third of children (9/26) had a strong relationship with a toy or fictional character



PDA *O'NIONS ET AL* 2017



Nearly three-quarters of the sample (19/26) reportedly took on borrowed personas or styles



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PDA AND INTELLECTUAL DISABILITY

**Case study: a young person with
Dravets syndrome, ASD, Epilepsy
and Intellectual Disability**

Very “challenging behaviour”

“the Hulk” ..Ripping his shirts

**Fantasy from preferred videos,
Captain Feathersword from the
Wiggles**

**Repeatedly replays favourite role
with other chosen person**



“EXCLUDED FROM SCHOOL”

BY BREDE, REMINGTON, KENNY, WARREN AND PELLICANO, 2017

Autistic students’ experiences of school exclusion and subsequent re-integration into school

9 students and their parents were interviewed

Positive outcomes were identified with attending an Inclusive Learning Hub model of education

National Autistic Society images



Welcome to the
2019 ASID conference
I trust that you are enjoying yourselves.

I would like to introduce myself.
My name is Appleby.





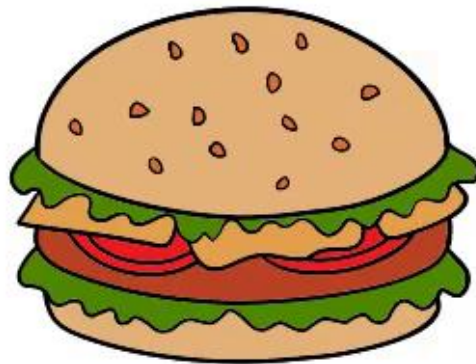
I have been asked here today by two wonderful educators
(shhh don't tell them that, it will go straight to their heads)
from Ascot Park Primary School in South Australia...

Michelle Miller (Mila) and Micheline Clark (Valentina)



I am the Head Administrator of LIPPI Travel
(formerly PC Agency).

I specialise in Daily Requests and Sandwich fillings.





My job is to send Daily Requests (learning tasks) to LIPPI Travel.

These tasks are sent from the CEO to me. I then write the requests (or missions) for the day and send them to Manager SuperNova (our student) at LIPPI Travel.

It is up to the Manager to complete the tasks with the help of her agents.

I answer directly to the CEO.



Mila (Michelle) and Valentina (Micheline)

and our fabulous
SSO Leah...



I am now going to leave it up to Michelle and Micheline to navigate you through the analogy of their PDA learning sandwich. They will explain their highly successful educational approach for teaching a student with PDA. Are you prepared for the trip of a lifetime?



Pack your bags and prepare for take-off.
At LIPPI Travel the possibilities are endless!



Enjoy!



Obstacles facing educators who are teaching students with PDA

- An understanding of PDA and PDA best practice for implementing a successful program
- Funding
- Teacher Training
- Support from educational leaders
- Excessive, increased anxiety = violent outbursts
- Dedicated space

What makes a good sandwich?



TEACHERS



THE STORY WITHIN THE STORY



THE STORY



THE HOOK



STUDENT



STUDENT

- ✓ Female
- ✓ 11 years old
 - ✓ ASD
 - ✓ PDA
- ✓ Vision Impairment
- ✓ Low emotional age
- ✓ Extreme sensory aversion for all of the senses
 - ✓ Small social circle
 - ✓ Humorous
 - ✓ Imaginative
 - ✓ Eurovision



THE HOOK

Listening to student – knowing what is babble and what is a possible interest or fascination.

This is heavily related to the RELATIONSHIP you have with your student.

Pervasive thought process/interest that is referred to out of context to the activity being done.

In our case, 'The Russians'



THE STORY

Each person/character in the learning space has a whole identity and background story.

The Barbies in our learning space are not just Barbies – each Barbie has an identity and purpose.

When we introduce a new Barbie into the room for a specific theme, the Barbie needs to have a whole background story.

Barbies take the demand/pressure off the expectations of the student.





THE STORY WITHIN THE STORY

The Juicy Bits

Everything has a purpose. There is no idea or learning activity that is implemented without thorough consideration of the story and the characters and what our student needs at the time.

Demand is reduced by having the characters struggle with issues that may directly affect our student or skills that she needs to learn.

The characters need help with something.
Our Students has the superior knowledge and skills to help the character.

Learning is embedded within the story.



TEACHERS

The demand-givers

The demand-reducers



An example from one day:

Planning a trip to the Maldives for our clients.

Curriculum Links

Numeracy: [ACMNA030](#), [ACMNA 031](#), [ACMMG044](#), [ACMMG086](#), [ACMMG090](#)

Literacy: [ACELA1460](#), [ACELA1461](#), [ACELY1666](#), [ACELY1789](#)

Science: [ACSSU031](#), [AC SIS037](#), [AC SIS038](#), [AC SIS041](#)

HASS: [ACHASSI034](#), [ACHASSI036](#)

The Arts: [ACAVAM108](#)

Personal and Social Capability Learning Continuum:

- Understanding Relationships [1b](#)
- Work Collaboratively [1b](#)
- Develop Self Discipline and set goals [1a](#)
- Work independently and show initiative [1a](#)

Monday

PRIOR KNOWLEDGE

4/3/19 LIPPI Travel Island Resort Options

Economy - \$50pp/pn

- breakfast \$5 (continental) \$7 (Full English)
- digital services incl.
- photo shoot (1 photo included with the option of buying more)
- Discount Coastline boat tour (was \$30 Now \$15) 50% saving
- \$40 submarine tour \$20 hotel transfers

Budget - \$30pp/pn

Nothing is included

Pay as you go

Freebie

- + \$40 submarine tour
- + \$30 hotel transfers

Maximum of 20 people (10am-4pm) per day

Day Trips

Extreme Budget - \$5 entry for a day trip

\$40 premium day ~~is~~ trip includes free access to pools and spas and free wi-fi.

Premium Economy \$70pp/pn

- Free 5GH wi-fi for entirety of stay
- Discount Scuba Pool access

+ all of the benefits of Economy

+ photo shoot (4 photos included with option of buying more) \$10 hotel transfers

+ \$20 submarine tour

Delux Economy \$100pp/pn

10GH internet - Premium * Free hotel transfers

\$20 Scuba pool entry

Free full breakfast and snacks

Lunch and dinner 50% off

Stand up paddle \$15 instead of \$30

Kayaks \$10 instead of \$20

+ all of the benefits of Premium Econon
+ \$10 submarine tour

Premium Pack \$1000/pp pp

EVERYTHING INCLUDED!

- + LIPPI Fashion and Accessories
- + All meals served by Butler in your own room
- + A la Carte Menu (Custom orders)
- + Champagne (unlimited)

- photo album + digital copy
- private access to other islands via speedboat
- FREE submarine tours
- Free hotel transfers

Premium Admin Pack \$10000 pp/pn

- You get the entire island to yourself
- Everything is free
- Personal butler
- Personal admin staff
- personal chef

Tuesday - Appleby's instructions for the day

Good Morning Manager,

I will be brief as the Russians are still around...

Today you have two new clients arriving at approximately 10am.

Complete the following before they arrive:

- Cut up fruit for our visitors arrival ✓
 - Choose some Yoga poses to take our clients through (all resorts offer yoga activities) ✓
 - Organise the 'Under Sea' Jellyfish decoration
 - Design the LIPPI Travel swimsuits and 'cover-alls' ✓
 - Practice our LIPPI Travel greetings ✓
 - Find Flight prices for our clients to compare
- | | | |
|---------|----------------|----------------------------|
| \$ 1006 | CATHAY PACIFIC | ADL - HK - M
(36 HRS) |
| \$ 1685 | SINGAPORE | ADL - SING - M
(17 HRS) |

When our clients arrive:

- Greet our clients
- "Hello, Welcome to LIPPI Travel. How can we help you today?" ✓
- Offer food and drinks ✓
- Offer a complimentary hand massage (Mila to do) ✓
- Organise a passport and flight ticket for each of the clients ✓
- Ask the clients to decide on their particular resort package ✓
- Convert Maldavian Rufiyaa to Australian Dollars for ✓
- Eg 5 MVR = _____ AUD and fill out the form to display in LIPPI Travel
- Complete the 'Shell find' activity ✓
- Play with the 'Mysterious Magic Sand'. Why is it magic? ✓
- Take 'Scuba Diving' photos of everyone ✓
- Complete the 'Sea Turtle' together

Have fun today! Appleby





Why is it successful?

- Based on current PDA Best Practice.
- Focussed on the child being at the centre.
- Relationship with our student.
- Relationship with each other
- 2:1
- Humour
- Imaginative
- On the spot ideas.
- Constant, meticulous planning
- Detailed daily reflections

Things to consider when educating a student with PDA

'The Hook'

Imagination

Flexibility

Committed educators

Success takes time

SERVICE S

WOMEN'S AND CHILDREN'S HEALTH
NETWORK

**HEALTH EDUCATION
INTERFACE**

KERRY RYE NURSE CONSULTANT

DEVELOPMENTAL DISABILITY MENTAL HEALTH NURSE

ASID CONFERENCE 2019



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EDUCATION”

The Health Education Interface

**A new initiative funded by the Department for Education-
commenced in 2018**

Currently funded for 3 years

The service is provided by Health:

**Women’s and Children’s Health Network- Disability Services
WCHN**

HEI IN A NUTSHI



- Provides specialist disability health staff to support teachers of students with disability and complex emotional needs.
- Works with schools to interpret behaviour responses in the light of the students developmental disability profile in the classroom so that learning can continue.
- Offers a holistic, transdisciplinary approach where physical health and behaviour is considered in the context of mental health and emotional wellbeing.

WHERE IT BEGAN-

**The current service began as a trial/pilot program-
CEDARS**

**(Child Education Development Assessment Research
Service)**

An agreement between:

- **Disability Services (Disability SA)**
(Dept. Communities and Social Inclusion)

- **The Department for Education**
(Disability Policy and Programs)

- **SA Health –WCHN Disability Services**

- was trialled for 12 months with staff from the 3 services for 1 day per week-in-kind**
- WCHN Disability Services had an existing service which supported students at school with disability and complex physical health needs called Access Assistant Program (AAP)**
- Education were keen to better support students with an intellectual disability**
- The Centre for Disability Health was thought to be closing with the advent of the NDIS**
- Service delivery of CEDARS was in creating a parallel service to the existing AAP but in support of students with emotional health needs**

A TRIAL SERVICE- EARLY DAYS.. WHY?

Service requirements driven by:

- **increased referrals to both AAP -Disability health and DfE-education**
- **increasing behavioural and emotional concerns of students in the education system**

School staff were seeking support/ clarity

- **around mental health concerns, challenging behaviour, school refusal or with increasing absence and suspensions**

HEI 2018-2019



A new service was created and as with any new service, (and 3 government departments).....the service commenced with 1.6 FTE in the first 18 months

Since May 2019 we are building a team of:

- **Administration (boss)**
- **Developmental Disability Psychiatrist**
- **Medical Consultant**
- **Social Worker**
- **4 Nurse Consultants**

THE CURRENT PROGRAM

- School referral
- Criteria- Disability, complex needs and exhibiting behaviours of concern that put their social and emotional wellbeing at risk.
- Current enrolment at school
- Where the interface between emotional development, behaviour, physical and mental health is unclear

What it offers:

- Developmental disability perspective
- Statewide service
- Consultative

HEI super powers:

- school and home visiting, less limiting in service delivery.
- Transdisciplinary approach

CHALLENGES IN SERVICE DELIVERY

Defining disability-

- Education – functional needs and capacity to engage in education (recent changes to disability funding for high level needs)
- Health- easier defined for service delivery
(diagnosed disability)
- NDIS- offers some challenges to the students referred
(minimal/multi agency/communication.....)

“A kid shouldn't need a diagnosis to access help.” Dr Ross W Greene

WHERE DOES THIS SERVICE FIT?

Incorporating a service model that embraces physical and emotional health from a developmental perspective.....

Is it health –maybe?

Mental health- maybe?

Or is it-

Intellectual Disability Service- specific to reduced functional capacity with complex health needs – physical and emotional health?

Intellectual disability health needs are unique but do we have to squeeze requirements to make them fit into a service model?

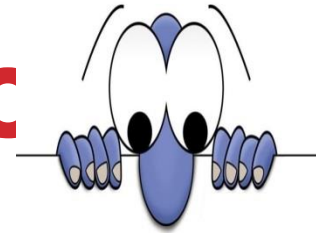
Health Education Interface is unique in it's service delivery

THE BACKSIDE

What we don't do- (not negative but definitive)

- **Replace existing or potential services for the student or the school site**
- **Prescribe medication - may recommend or suggest around the students presentation/ developmental profile**
- **Offer ongoing input (depending on complexity as to how long involved in supporting the school)**

FROM CEDARS TC



HEI established to:

- > **Cater for students with disability and a physical/emotional presentation**
- > **the interface between Health and Education**

Offers:

- > **Flexibility in service delivery-home/school-visits/education sites with behavioral focus**
- > **Assess emotional and developmental health needs in the school environment/home**
- > **Determining physical health needs that may be impacting on behaviours**
- > **Aids in interpreting behavioral concerns with a social/ emotional development focus; unique needs/ sensory concerns**
- > **Development of support plan for the student and school staff in reconnecting or maintaining an educational pathway.**

Outcomes:

Student presentation at school better understood

Offers improved social and emotional outcomes

Enhanced communication between health practitioners around the student



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