An Updated Interest Based Account (Monotropism theory) & a Demand Avoidance Phenomenon discussion

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An Updated Interest Based Account *(Monotropism theory)* & a Demand Avoidance Phenomenon discussion.

Richard Woods.
12\textsuperscript{th} April 2019.
Remembrance.

1) Deeply saddened by passing of Mike Oliver.
2) Likewise, by sudden death of Judy Eaton’s son.
PERSPECTIVE.

My Bias.

1) The speaker meets its proposed profile, but that does not mean much.
2) Demand Avoidance Phenomenon (DAP) Sceptical that DAP is an autism subtype or a syndrome.
3) Significantly more compelling research, in quantity and quality.
4) Speaker has never hated DAP.
5) Annoyed by its construct & it operation.
6) Good reasons to be antagonised by DAP.
CHEAP PLUG.

Autism Policy & Practice.

1) Open Access autistic-led good practice journal.
2) Access via link below:
   https://www.openaccessautism.org/index.php/app/about
3) Alternatively, contact Dr Mitzi Waltz.
   mitziwaltz@yahoo.com
Introduction.

1) Builds on previous talk on Monotropism and anxiety. (Woods 2018c).
2) What DAP is.
3) Case “against” DAP.
4) What is Monotropism.
5) Further refinement.
6) DAP discussion topics, plus Questions & Answers.
WHAT IS IN A NAME?

A Suitable Name.

1) Demand to change its name (Eaton 2018; Gillberg 2014; Milton 2017a; Newson et al 2003; PDA Society 2019; Reilly et al 2014; Sanchez 2018; Woods forthcoming).

2) DAP, *Demand Avoidance Phenomenon*.

3) Will be clear later why this is appropriate.
LET’S TALK.

Main DAP Discourse.

1) Called Pathological Demand Avoidance or Extreme Demand Avoidance.
2) A distinct syndrome.
3) An autism subtype/ Pervasive Developmental Disorder.
4) DAP *is* controversial (Falk 2019; Fidler and Christie 2019; Green et al 2018b; Kaushik 2015; O’Nions et al 2014a; O’Nions et al 2014b).
5) Dichotomy “for” & “against” sides.
DEPTH OF PERSPECTIVE.

DAP Controversy.

1) Substantial levels of disagreement with main discourse (Brede et al 2017; Dore 2016; Evans-Williams 2018; Fieldman 2018; Flackhill et al 2017; Garralda 2003; Green et al 2018a; Haroon 2019; Kaushik 2015; McElroy 2015; Malik & Baird 2018; Milton 2017a; Slaughter et al 2019; Wing 2002; Woods 2017).
DEPTH OF PERSPECTIVE.

DAP Controversy.

1) Highly contested, undermining credibility of all DAP “experts” (Vassilev & Pilgrim 2009), including the speaker.
2) Reciprocal claims to some: charlatans, extremists, gaslighting, spreading nonsense & unethical conduct.
TIME TO PROFILE YOU.

Autism + DAP Traits criteria.

1) Comfortable in role play and pretend.
2) Continues to resist and avoid ordinary demands of life.
3) Demand avoidance can use social strategies.
4) Lability of mood & impulsive.
5) Obsessive behaviour, often focused on other people.
6) Surface sociability, but apparent lack of sense of social identity, pride, or shame (Fidler 2019; Green et al 2018a; Newson et al 2003).
TIME TO PROFILE YOU.

Non-essential criteria.

1) Delayed Speech Development.
2) Neurological Involvement.
4) Sensory differences (Eaton et al 2018).
TWO FACES.

Citation Survey Results.

1) Main discourse is being challenged.
2) Key literature is being accessed thousands of times.
3) Key literature rarely references critical literature, except to support its case or disagree with critique.
4) Lack of autistic perspectives referenced.
5) Forming a community of practice.
A STATE OF MATTER.

Why this matters.

1) Overstating “for” case.
2) Reification (Rutter & Pickles 2016).
3) Potentially negligent assumptions (Dore 2016; Milton 2017a).
4) Nonsense, “atypical autism”.
5) Metaphors can be dangerous (Dinishak & Akhtar 2013; Goodley et al 2019; Hacking 2010; Walsh 2018).
A STATE OF MATTER.

Why this matters.

1) Ethically, a balanced perspective should be presented (Brooks et al 2014; Dawson 2004; Rutter & Pickles 2016; Waltz 2007).

2) Ramifications of community of practice can lead to sources of confirmation bias (Milton 2017a).

3) Undermines literature’s epistemic integrity (Milton et al 2018).
Profile limitations.

1) DAP criteria is unstable (Eaton 2018a).
2) No agreement over diagnostic criteria & are not consistently applied.
3) No agreement on how to do diagnose DAP.
4) DAP profile overlaps autism behaviour profile (O’Nions et al 2018).
TIME TO PROFILE YOU.

Profile limitations.

1) Autism dx from age 3+, as when behaviours consistently manifests (Green et al 2018).

2) “Passive Early History” & Avoidant behaviours are generic, with anecdotal evidence open to confirmation bias.

3) Assumptions on ontology, nosology & aetiology of DAP should avoid anecdotal evidence.
THE OTHER SIDE.
Non-Specific Nature.

1) DAP has no specificity (Attwood 2018; Christie et al. 2012; Christie & Fidler 2015; Garralda 2003; Malik and Baird 2018; PDA Society 2019; Wing 2002).

2) Signs of DAP seen in Asperger’s case studies (Falk 2019; Philip & Contejean 2018; Sanchez 2018).

3) At least 15 medical ontologies, including many common autism comorbidities (Woods 2018c).

4) Large overlap between many of these (Rutter & Pickles 2016).
Non-Specific Nature.

1) Such co-morbidities are being seen in recent samples (Brede et al 2017; Eaton 2018b; Egan et al 2018; Kaushik 2015; Lyle & Leatherland 2018; Trundle et al 2017).

2) Interaction with comorbidities affects autism development (Brede et al 2017; Flackhill et al 2017; Green et al 2018a; Verhoeff 2012).
THE WRONG SPECTRUM.

Part of the Spectrum?

1) DAP is autism subtype due to high anxiety levels & Theory of Mind issues (Christie & Fidler 2015).

2) Anxiety is not part of the autism diagnostic criteria (Woods 2018a).

3) Theory of Mind issues are found outside of autism, including attention deficits, LD & Schizophrenia (Lawson 2011).
THE OTHER SIDE.

The “Against” Case.

1) Atypical nosology (Green et al 2018b).
2) Autism subtypes lack validity, including Asperger’s and DAP (Green et al 2018a; Happe 2011).
3) ASD+PDA traits dual diagnosis has not always been used, e.g. Elizabeth Newson Centre started using it 2015.
4) DAPers originally being diagnosed with Atypical Autism or PDD-NOS (Christie et al 2012; Newson et al 2003), were already being diagnosed as autistic.
THE OTHER SIDE.

Remission rates.

1) O’Nions et al (2016a) suggests a 40% remission rate.
2) Gillberg et al (2015) 1 out of 9 persons meeting profile into adulthood; 90% remission rate.
THE OTHER SIDE.

Result of trauma?

1) The behaviours can be caused by other conditions, resulting from trauma (Brede et al 2017).

2) Egan et al (2018) suggests behaviours are caused by personality, not autism.

3) Some DAPers showing signs of emerging Personality Disorders (PDA Society 2019).

4) Personality Disorders are caused by trauma (Fieldman 2018).
AUTISM MANIFOLD?

Measuring problems.

1) Difficult/ impossible to measure boundaries between subtypes.

2) Autistic persons frequently transition between subtypes (Leatherland 2018; Wing 2002; Wing et al 2011), including in different situations (Verhoeff 2012; Walsh 2018; Watts 2017; Woods 2018b).

3) Lack sense of identity/ pride/ shame are hard to measure (Garralda 2003).

4) Using questionnaires & lacking specific items from using caregiver reports (Lord et al 2018).
AUTISM MANIFOLD?

Possible sources of bias.

1) DAPers are prone to internalising (Woods 2018b), & showing signs of such.
2) Plausible confirmation bias from DEP & divergent stakeholder perspectives (Woods 2018a).
3) High risk of confirmation bias via looping effects (Heasman & Gillespie 2018; Loomes 2019).
4) Risk of confirmation bias due to vague questions, behaviours that are not unique & reliance on caregiver reports.
THE OTHER SIDE.

Alternative results explanations.

1) DAP will lead to confusion (Garralda 2003; Green et al 2018b).
2) Plausible conditioning into DAP profile (Woods 2018b).
3) High anxiety levels can be partly explained by masking (Goffman 1963).
DOWNING TOOLS.
Screening & diagnostic tools.

1) Extreme Demand Avoidance Questionnaire is a screening tool; EDA-Q.
2) EDA-Q flaws: has a rater bias (Green et al 2018a) and divergent scores across stakeholders (Brede et al 2017).
3) EDA-Q flaws: has not been standardised (Summerhill & Collett 2018).
4) EDA-Q flaws: Detects demand avoidance behaviours in other conditions & false positives (Eaton 2018b; Green et al 2018; Kaushik 2015).
Screening & diagnostic tools.

1) Diagnostic Interview for Social and Communication Disorders; DISCO.
2) DISCO flaws: Does not take into account fantasy and roleplay traits (Philip and Contejean 2018).
3) Questioned if objective measures can be developed (PDA Society 2019).
TOP CONDITION?

Behaviourism in DAP.


3) Changes in behaviour can be from many factors, including those not considered in practice (Milton 2017b).
A VALID QUESTION.

Research approach.

1) Started from their understanding of autism & then to investigate if behaviours are found elsewhere (O’Nions et al 2016b; PDA Society 2019).
2) Research needed to support clinical based understandings as an autism subtype (Christie et al 2012).
3) DAP needs to be autism subtype to fall under Autism specific legislation & guidelines (Christie & Fidler 2015).
A VALID QUESTION.

Research approach.

1) DAP needs reliability over validity (Christie 2018), ignoring present validity based autism nosology (Green et al 2018b; Happe 2011).
2) To maintain integrity of how DAP is understood & nature of support (Christie 2018).
3) Mainly using deductive/ circular methods.
THE OUTLOOK.

Pertinent Issues.

1) Extremely difficult for anyone to credibly claim to know what DAP is with lack of evidence & DAP’s systemic flaws.
2) Pluripotential nature of its’ behavioural profile and subjective symptoms means any condition can be identified as DAP if one is looking for it (Woods, submitted).
3) Significant sized minority of DAPers are likely to be non-autistic (PDA Society 2019).
4) Most current DAP research can be viewed as self-validating pseudoscience.
THE OUTLOOK.

Pertinent Issues.

1) DAP seems to not lower formal exclusions, yet, raises informal exclusions (PDA Society 2019).
2) DAP is not a recognised research priority of autistic persons (Woods 2017).
3) DAP is the only certainty some vulnerable persons have, e.g. as a shield from parent blame.
4) “Lightbulb moment” is used as justification for utilising DAP.
TIME TO STRATEGISE.

Overlapping Strategies & Pedagogies.

1) Autism Catatonia (Eaton 2018a).
2) Autistic preferred approaches (Laurent 2019; Milton 2018b).
4) Dielectric Therapy (Eaton 2018a; Fieldman 2018).
5) Evidence based practices (Green et al 2018b).
6) Inquiries based learning.
7) SPELL Framework (Milton 2017a).
ANOTHER STATE OF MATTER.

Contextual Issues.

1) Autism traditionally has poor quality ethics and research (Waltz 2007). This is still ongoing, e.g. Applied Behavioural Analysis/Positive Behaviour Support and Autism Innovative Medicine Studies.

2) DAP viewed as a threat to (hard won) validity of clinical language (Green et al 2018b).

3) American Psychiatric Association/World Health Organisation/Autistic persons place to decide what is and is not autism.

4) Similarly, for DAP.
ANOTHER STATE OF MATTER.

Contextual Issues.

1) Ethically, DAP needs good quality evidence to be used (PDA Society 2019).
2) Following DAP logic to nosology (DAP has specific strategies); it could be viewed as form of Catatonia & Personality Disorder, due overlap in perspective strategies.
3) Some argue autism is only a cultural construct (Runswick-Cole et al 2016).
4) Likewise, autism is an artefact of diagnostic practice (Walsh 2018).
THE TWILIGHT ZONE.

The Null Hypothesis.

1) Prioritise integrity & validity of autism, over diagnosing DAP.
2) Scientific knowledge is driven by disproving null hypothesis.
3) “Until proven otherwise, is that there is no characteristic natural entity that can be elicited and reliably measured/identified that corresponds with Demand Avoidance Phenomenon”.
4) Adapted from Timimi (2018).
THE QUICKENING.

Summary.

1) Covered core issues against DAP.
2) Contextualised DAP relevant discourses.
3) Arguing for scientific approach to DAP to maintain integrity & validity of autism.
4) Switching to Monotropism.
AN INTEREST BASED ACCOUNT.

Monotropism 101.

1) Attention is a scarce resource, there is competition for its use by myriad interests.
2) An interest is anything that gains your attention; from sensory stimuli, thoughts to emotions.
3) Each person can only process a certain amount of attention resource at any moment.
4) Continuum of perceiving attention; One end is Monotropism and the other Polytropism.
5) Autistic persons tend to be monotropic.
6) Non-autistic persons tend to be polytropic.
AN INTEREST BASED ACCOUNT.

Monotropism 101.

1) Attention tunnels are made from attention resource.
2) Monotropism is with a single attention tunnel when entire attention resource is used.
3) Polytropism is with many attention tunnels that have similarly distributed attention resources.
Single attention tunnel leads to:

1) Interests are processed sequentially in order of importance.
2) Experiencing intense sensations.
3) Binaric black and white thinking.
4) External information being occluded from awareness.
5) Intensity of our thoughts leave stronger impression on subconscious.
6) More difficult to restart attention tunnels.
CONFLICTING INTERESTS.

An Interest Based Account Reading.

1) For further reading see (Murray et al 2005): https://www.researchgate.net/publication/7879954_Attention_monotropism_and_the_diagnostic_criteria_for_autism
2) The Passionate Mind (Lawson 2011).
3) Monotropism - An Interest Based Account of Autism (Murray 2018).
GOING WITH THE FLOW.

Flow States.

1) An optimal experience that is beneficial to our wellbeing and happiness.
2) Experienced when a person is deeply involved in an activity and nothing else seems to matter.
3) Flow states can happen in social interaction.
4) Provide stability, e.g. an escape from anxiety.
5) Such activities that engage with flow states can become a compulsion and addictive.
6) Aversive to chaotic life outside of the person.
7) (McDonnell & Milton 2014).
Clumping Attention Resource.

1) Where the flow of attention resource is halted due to sticking together.
2) Can form blockages to prevent attention resource bringing certain information into person’s awareness.
3) (McDonnell & Milton 2014).
IN THE LOOP.

Biolooping.

1) How a person’s mental state affects their physical state.
2) Vice versa.
3) A person thinking they are ill, can make themselves ill.
4) Again, vice versa.
5) Yoga.
6) (Hacking 1999).
DEVELOPMENTAL TRAJECTORY.

Developing Monotropism.

1) N = Attention Resource (Murray 2018).
2) A = Anxiety.
3) F = Flow states. Duration and intensity of a flow state.
4) R = Stored N. Depleted by persons using N
DEVELOPMENTAL TRAJECTORY.

Developing Monotropism.

1) C = Capacity: N that is available for use after automatic cognitive processing; forming the perception based on sensory inputs and any intrusive thoughts that consume R before it can be used for day-to-day tasks (Murray et al 2005).

2) Higher F = Higher N and Lower A.

3) Higher F → Higher C.

4) Higher F → Higher R.
Monotropism and anxiety.

1) All humans (and animals) need stability.
2) Points of interest can be stability points.
3) Black/white thinking style. Either have certainty/uncertainty on a subject.
4) Obscure other thoughts that are linked to the subject of interest; obscure & reduce anxiety.
5) Therefore these flow states form fixed points of stability for autistic persons.
AN ANXIOUS MOMENT.

Monotropism and anxiety.
1) Autistic persons engage with subjects that interest them.
2) Requires significant N to engage with uninteresting matters.
3) Explains autistic social communication issues.
4) When a person has no N and an attention tunnel is violently disrupted, an autistic person can lose control; go into meltdown/shutdown/panic attacks.
5) Autistic persons will tend to have higher anxiety levels due to black and white thinking.
REMEMBER, JUST BREATHE.

Monotropism and anxiety.

1) Autistic persons being 1-2% of population and not interested in non-autistic social norms; they have different sources of stability.
2) Polytropism easily engages in social interactions; thus forming flow states from it.
3) Non-autistic benefiting from lower anxiety and increased R.
4) Non-autistic stability also comes from understanding non-autistic social interaction and being able to rely on this consistently.
AN ANXIOUS MOMENT.

Flow state Example & Implications.

1) Autistic person’s breakfast routine, allows person to function for rest of the day.
2) Autistic person is in a flow state from that routine.
3) Benefiting from reduced anxiety and increased N. If it is a flow state present from the routine, it would be a fixed point as explained by Monotropism.
4) Regular low levels of R and C over extended time periods can lead to trauma and anxiety.
REMEMBER, JUST BREATHE.

Polytropism & Anxiety.

1) Non-autistic persons can experience inconsistent social interaction.
2) “Some staff also find it anxiety provoking to spend extended periods of time with another person who is anxious and has mood swings. This group of pupils can be very intense to work with, which is tiring” (Fidler and Christie 2019, p. 140).
3) Anxiety here can also be explained by masking (Goffman 1963).
Polypotropism & Anxiety.

1) DAP parents often have higher anxiety levels than either autism parents & CD parents (Durà-Vilà & Levi 2019).

2) Correlation between parents with high anxiety & children with high anxiety (Howard 2017).
BACK TO MODELS.

SOR Developmental Model (Howard 2017).
SINGLE FOCUS.

Monotropism DAP Model.

1) Howard Model can be adapted for Sensory Under Responsivity & Monotropism.
2) Monotropism uses an embodied mind/environment feedback (Murray 2019).
3) Crucially, this from birth.
A SNUG FIT.

Monotropism DAP Model.

1) Autism + Environment = Outcome (Beardon 2017, p11).
2) Environment component uses DEP & “Goodness of fit” (Green 2016; Milton 2018).
3) Thus, is transactional.
4) Matching environment to individuals needs (Green 2016).
5) Preschool Autism Communication Trial; PACT intervention.
PEAK INTEREST.

Monotropic developmental peaks.

(Murray 2019).
PEAK DISTRICT.

Polytropic developmental peaks.

(Murray 2019).

Fuzzy boundaries, massive interconnectedness
PEAK INTEREST.

Monotropic developmental peaks.

(Murray 2019).
MATCHING SALIENCES.

Environmental Impact on development.

1) More synchronised environment to autistic’s interests, the more opportunities to enter flow states.
2) Thus, autistic person will have more fixed points.
3) Likewise, higher Global Stability levels.
4) Activities that are fixed points are over time internalise to be part of autistic’s identity.
5) E.g. Harry Thompson responding to dares (2019).
6) Or my bad jokes.
MIS/MATCHING SALIENCES.

Environmental Impact on development.

1) More an autistic’s external environment is matched to their interests.
2) The more densely connected their peaks.
3) Likewise, more external connections between their peaks.
4) Autistic persons can loose sense of self from trauma (Milton 2017c).
5) Due to connections between peaks severing & possibly the shattering of peaks.
MISMATCHING SALIENCES.

Impact of trauma on development.

1) Process can be exacerbated by experiencing distressing situations.
2) Can internalise distressing response.
3) Creating a destructive feedback loop.
4) Traumatic experiences can shatter autistic persons fixed points.
5) This forces individuals to search for different activities they can enter flow states with.
MISMATCHING SALIENCES.

Impact of trauma on development.

1) If an autistic person is repeatedly traumatised, they can gradually shift from automatically responding to dares to controlling their food intake. E.g. Thompson (2019).

2) Or retreat to other “extreme” activities as sources of fixed points, increasingly entering fantasy worlds.
MISMATCHING SALIENCES.

Impact of trauma on development.

1) This matters, as over time from repeatedly entering a flow state by rituals controlling food intake, these become fixed points.
2) Then internalised to become part of the person in a form of an eating disorder.
3) Applicable to other “extreme” fixed points.
4) Autistic persons need environments we can easily enter flow states with many different sources.
5) *Give us control of our routines; Structure part of SPELL Framework* (Milton 2014).
MISMATCHING SALIENCES.

Easier said than done.

1) Autistic infants can be startled by “trivial” interactions with carers.
2) With monotropic processing, infant may not recognise they are in a safe situation when being hugged; thus is shocked.
3) Can occur repeatedly.
4) Often not carer’s fault.
A STARTLING REVELATION.

Easier said than done.

1) Startled infants could become hyper aware and sensitive to their sensory environment.
2) Rises intolerance uncertainty & thus anxiety.
3) Carers told to follow standard parenting advise raises mismatch between environment & infant.
4) Generates cycle that deteriorate infants & carers wellbeing.
5) Often not carer’s fault.
6) Can explain DAP behaviour in infants.
7) Needs strategies that works with the child.
AVOIDANCE OF DOUBT.

Modelling DAP.

1) DAP fixed points tend to be fantasy, role play & “challenging” behaviour. E.g. automatically responding to dares (Thompson 2019).
2) Can be problematic leading by creating substantial mismatch between autistic & environment, leading to possible trauma.
3) Essentially views DAPers as traumatised autistics.
ROUND TABLE.

Summarising.

1) Strong scientific case against main DAP discourse.
2) Scientific approach is needed to maintain integrity & validity of autism.
3) Monotropism can explain anxiety in autism.
4) Developmental model places importance on matching environment to child.
5) Autistic trauma is often not the carers fault.
POSITIVE FEEDBACK.

Acknowledgements.

1) I thank the following for commentary on development of this talk: 
2) Carl Cameron, Judy Eaton, Jonathan Green, Damian Milton, Dinah Murray & Harry Thompson. 
3) Andy McDonnell, Fergus Murray & Catriona Stewart for having faith in my theorising. 
4) Luke Beardon for his Global Instability Theory that inspired the previous talk.
ANY QUESTIONS?

The End Game.

1) Contact Details: richardwoodsautism@gmail.com
2) Twitter handle: @Richard_Autism
4) Any questions?
Options for discussion.

1) DAP criteria.
2) Steph’s Two Girls quote.
3) Judy Eaton observation.
4) Fidler and Christie matching the dials concept.
5) Milton’s Syndrome thought experiment.
6) Monotropism; specificity, uniqueness & universality.
READY PLAYER ONE?

Autism + DAP Traits criteria.

1) Comfortable in role play and pretend.
2) Continues to resist and avoid ordinary demands of life.
3) Demand avoidance can use social strategies.
4) Lability of mood & impulsive.
5) Obsessive behaviour, often focused on other people.
6) Surface sociability, but apparent lack of sense of social identity, pride, or shame (Fidler 2019; Green et al 2018a; Newson et al 2003).
1) “For years now, Sasha has controlled the music in the car, and we have one CD on repeat for weeks or months at a time. From any one CD, there is usually only a handful of songs at most which can be selected; I think I’ve become immune to the repetition but am sure others would find it unbearable if they joined us regularly on our journey. It's become apparent in the last few days that Sasha now needs to listen to certain songs at a certain time in the journey” (Curtis 2018).
THREE’S A CROWD.

Judy Eaton’s Controlling Food Intake.

1) Often go into meltdowns etc. when pushed to follow another’s direction.
2) These persons are externalisers.
3) Punished for displaying clear emotions/making mistakes.
4) Internalise their anger & frustration.
5) Thus to prevent further social isolation, person control their food intake (behaviour) instead of other persons to manage their anxiety.
6) (Eaton 2018, pp. 146-147).
THE FOUR CASE.

Fidler & Christie, Matching The Dials.
1) Person has a threshold capacity to demands, determined by their anxiety levels.
2) There are 2 dials.
3) First for a person’s tolerances to demands.
4) Second for person’s levels of experienced demands.
5) If first dial is high, demand and expectations can be raised.
6) If first dial is low, demand and expectations should be lowered.
7) Synchronise dials as much as possible.
8) (Fidler and Christie 2019, pp. 26-27).
Milton’s Syndrome Thought Experiment.

1) What if the autistic population proposed an autism subtype, called “Milton’s Syndrome”?
2) This scenario Milton’s Syndrome has same issues DAP has.
3) What would be the response to Milton’s Syndrome?
Specificity, Uniqueness & Universality.

1) Specificity = “does autism arise from a domain-specific factor or are multiple factors involved?”.

2) Uniqueness = “Is the factor unique to the disorder or is it also involved in other developmental disorders?”.

3) Universality = “Is the factor (or factors) found in every individual with autism or just in the majority?” (Rajendran & Mitchell 2007, p224).
Bibliography.


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