

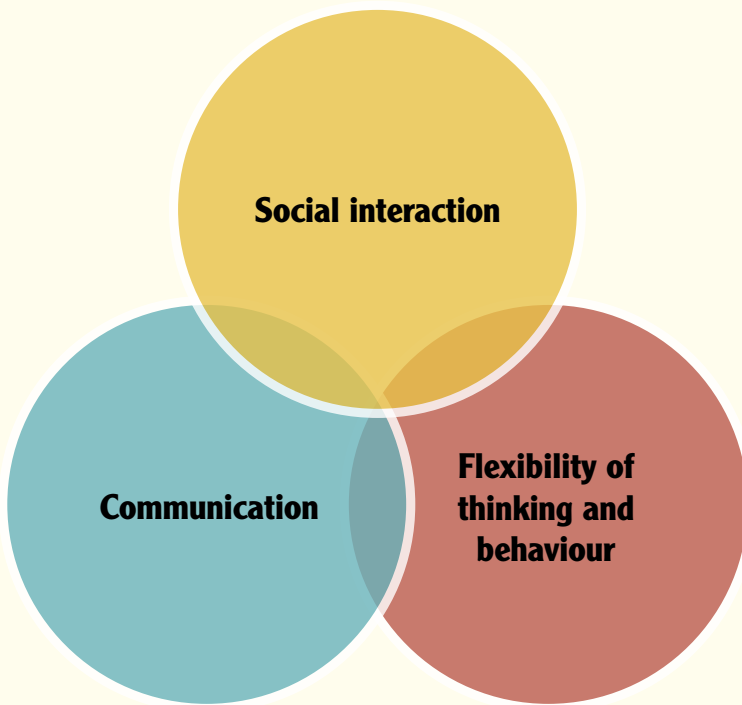
# Understanding **Extreme Demand Avoidance (EDA)**

as a profile of the Autism Spectrum

South Lanarkshire Council  
guide to strategies to support  
Children and Young People with EDA

# What is Extreme Demand Avoidance (EDA)?

In Autism, individual profiles can vary considerably depending on the combination of a person's strengths and difficulties. The core difficulties of Autism are difficulties with social communication and flexibility of thinking.



EDA describes a rare profile of these difficulties that gives rise to an extreme anxiety response to perceived demands and expectations. All behaviour is communication. Controlling behaviours in EDA are often communicating extreme anxiety. In order to offer appropriate support, staff need to recognise how the young person is experiencing the environment. Understanding this will allow staff to adapt the physical and communication environments, particularly in terms of how demands are presented. It will also enable staff to understand what skills and knowledge a young person needs to develop in order to cope.

# How does Extreme Demand Avoidance EDA present itself?

Please be clear that EDA is recorded in the diagnostic process as a profile of ASD. Some pupils may not yet have their diagnosis and this list will aid practitioners in this case.

## Child or young person may:

- Resist and avoid the ordinary demands of life in a panic driven, extreme manner – refusing, giving excuses, distracting, changing topic, negotiating, bombarding with questions/noises, withdrawing to a fantasy world, extreme role playing.
- Appear sociable, but lack depth in social understanding. Poor social awareness of hierarchy and uninterested in forming lasting relationships.
- Have excessive mood swings and impulsivity.
- Have had childhood language delay, often with good degree of catch-up.
- Display obsessive behaviour, often focussed on people.
- Sometimes appear to be domineering, controlling and overbearing.
- Appear more comfortable with adults than children- sees self as an adult.
- Shut down.
- Threaten physically or verbally- hits weak spots and appears manipulative.



# What strategies can be effective?

Every individual with Autism will have a different profile of strengths and challenges. It is important to develop a rich understanding of the child/young person and to consider what aspects of processing are leading to the behaviours you are concerned about. It is essential to consider how all aspects of Autism may be contributing to difficulties. This should be done using the **ASD Consultation Approach**. After considering the main aspects of the psychology of Autism, it can be useful to reflect on the possible demands in a given situation. A version of the ASD Consultation framework, with Demands included as an additional factor, is available from Inclusive Education and Psychological Services.

Assessment and planning should also reflect the 'Promoting Positive Relationships and Understanding Distressed Behaviour' guidelines.

Interventions should be designed around the unique profile of the individual and their context.

## 5 golden rules to consider when planning supports are:

1. Think ahead
2. Give advance notice
3. Monitor stress levels and scale back demands
4. Create space
5. Keep calm

It can be useful to consider strategies under the following themes:

## How staff relate to the child/young person:

- Relationship building is key, using a calm, positive manner to build genuine connection.
- Understand that the demand avoidant behaviours arise from severe anxiety and are not a choice.
- Ensure a variety of staff work with the young person to reduce reliance on one person.
- Recognise positives and share these indirectly to change expectations.
- Encourage the young person to recognise their own strengths and successes.
- Allow the young person to share control of what and how they learn.
- Use rules flexibly, recognising the difference between those that are essential and those that are desirable. Demonstrate flexibility in applying these to alleviate anxiety.

## Communication:

- Use visuals to support understanding, at a level appropriate to the individual.
- Reduce language and leave extended pauses for understanding.
- Phrase demands in a non-direct manner (“I wonder if...”, “Teachers usually think this is a good idea because...”).
- Explicitly recognise the young person’s perspective (“I know you hate washing your hands.”).
- Challenges sometimes work. (“I wonder if you could...”).

## Behaviours:

- Collaborate about rules and targets.
- Use the young person’s ideas where you can.
- Be prepared to do things differently to how they have always been done, if other ways achieve the same end point.
- Explicitly concede where you can.
- Role playing potentially challenging situations can sometimes help.
- Moderate demands on the young person’s ability to cope on any given day.



# Supporting pupils with an EDA profile

Traditional school approaches, even positive ones such as rewards and praise, can feel like unbearable demands to some pupils. Effective support for these pupils is **flexible, co-operative and aims to understand their unique perspective**. This can be effectively planned using the ASD Consultation Approach, incorporating the principles outlined in this leaflet.

## Strategies to avoid:

- Reward systems are often ineffective as the individual with EDA feels out of control.
- Inflexible, adult set rules and routines.
- Unwillingness to try to understand the nature of the behaviour - it is an incapacity and is not a choice.
- Confrontation.

**Try to understand that EDA is a disability where a child or young person is struggling in an extreme manner to make sense of a world they find perplexing.**



## Recommended reading and useful links:

### Extreme Demand Avoidance Syndrome

A reference booklet for Health, Education and Social Care Practitioners  
([www.pdasociety.org.uk](http://www.pdasociety.org.uk))

### Simple strategies for supporting children with Extreme Demand Avoidance at School

(Zoe Syson and Dr Emma Gore Langton)

### Educational and Handling Guidelines for Children with Extreme Demand Avoidance Syndrome

(Professor E Newson, Early Years Diagnostic Centre, Nottingham)

- [www.nas.org.uk](http://www.nas.org.uk)
- [www.sutherlandhouse.org.uk](http://www.sutherlandhouse.org.uk)
- [www.pdasociety.org.uk](http://www.pdasociety.org.uk)
- [www.thepdaresource.com](http://www.thepdaresource.com)
- Understanding PDA in Children Phil Christie.
- Can I tell you about PDA? Fidler and Christie

\* Strategies recommended to meet the needs of those with EDA can be effective in meeting the needs of those with Trauma, Attachment and Stress Disorders in that they may need to feel in control to lower their anxiety. However, one must have an ASD diagnosis in order to have an EDA profile.



If you need this information in another language or format, please contact us to discuss how we can best meet your needs.

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