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IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Evidence-informed Advice for Parents, and Education and Healthcare Practitioners

Dr Alison Doyle and Dr Neil Kenny

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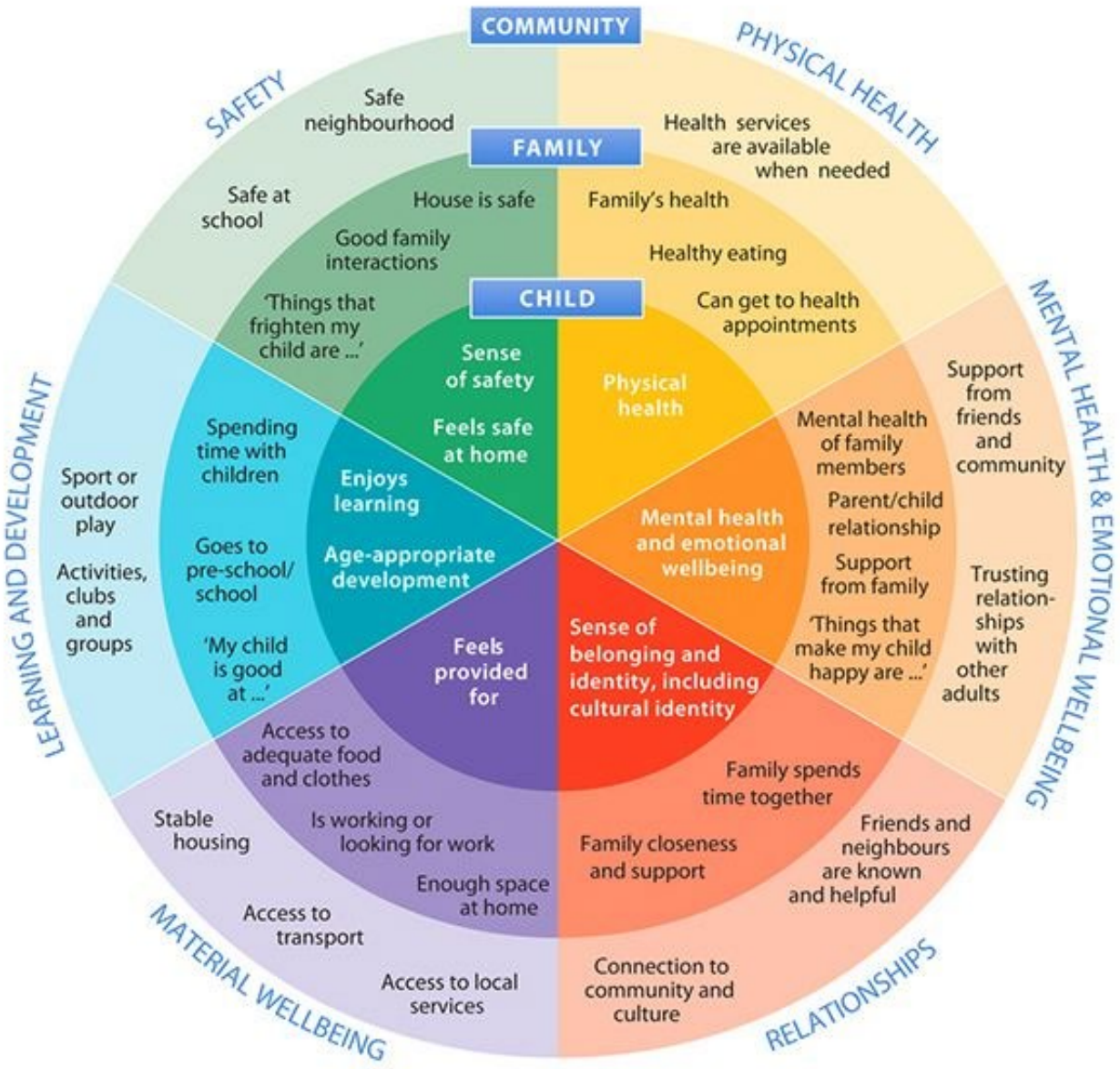
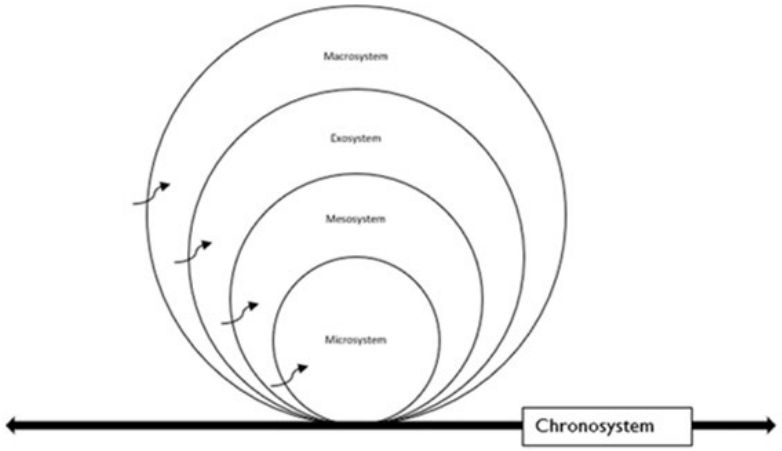
DCU Institute of Education

Overview & Aims

- To encourage you to reflect on your own practice or the practice within your school
- To share your professional experience of barriers/solutions to parental involvement/collaboration
- Practical applications





Macrosystem
Legal frameworks and definitions e.g. UNCRC, CRPD, EPSEN, Disability Act, School Admissions, Autism Bill, NCSE and HSE policies, directives from teaching unions, teacher training standards, resourcing of multi-disciplinary teams, separation of diagnoses e.g. autism and mental health

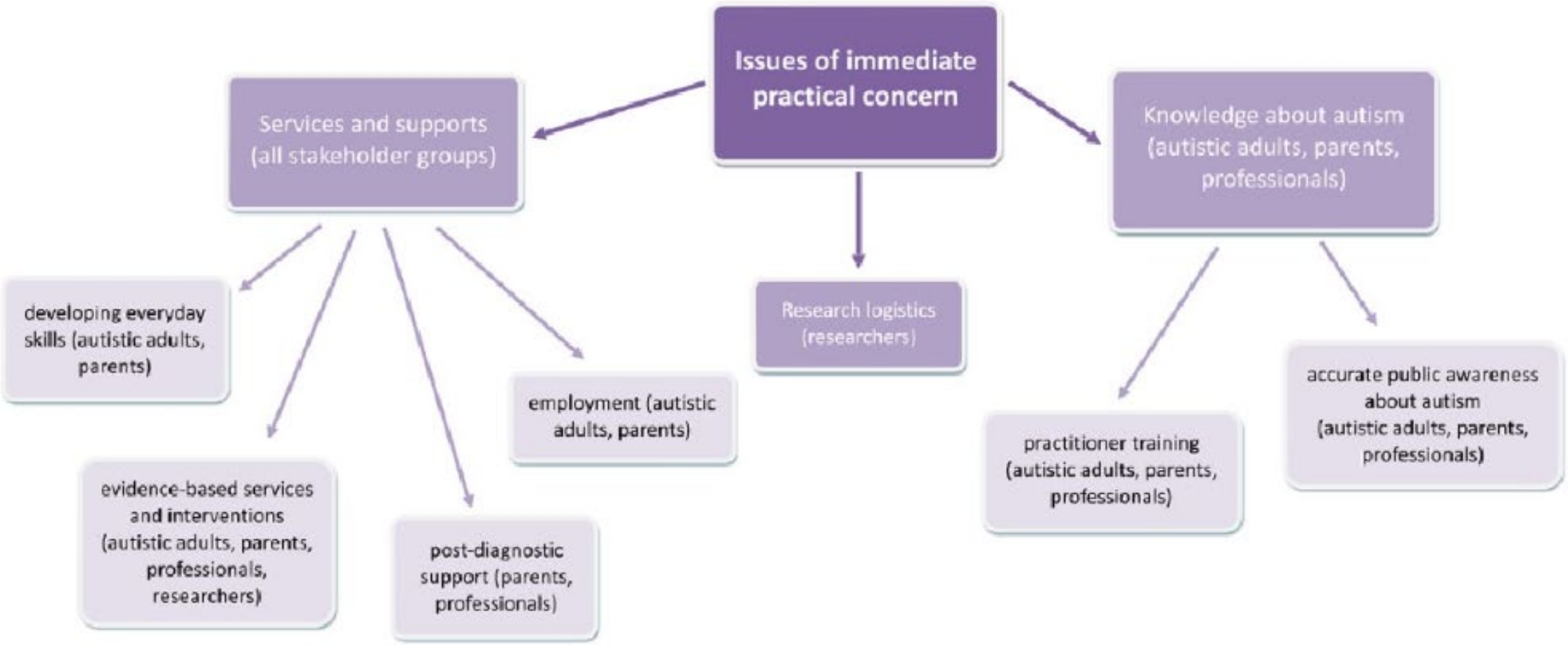
Exosystem
Primary and secondary education: physical infrastructure, sensory environments, autism units / autism classes, reverse inclusion, NEPS Continuum of Support, models of resource allocation, role of SNAs, importance of CPD, delays in Assessment of Need and service statements, under-resourcing of autism expertise

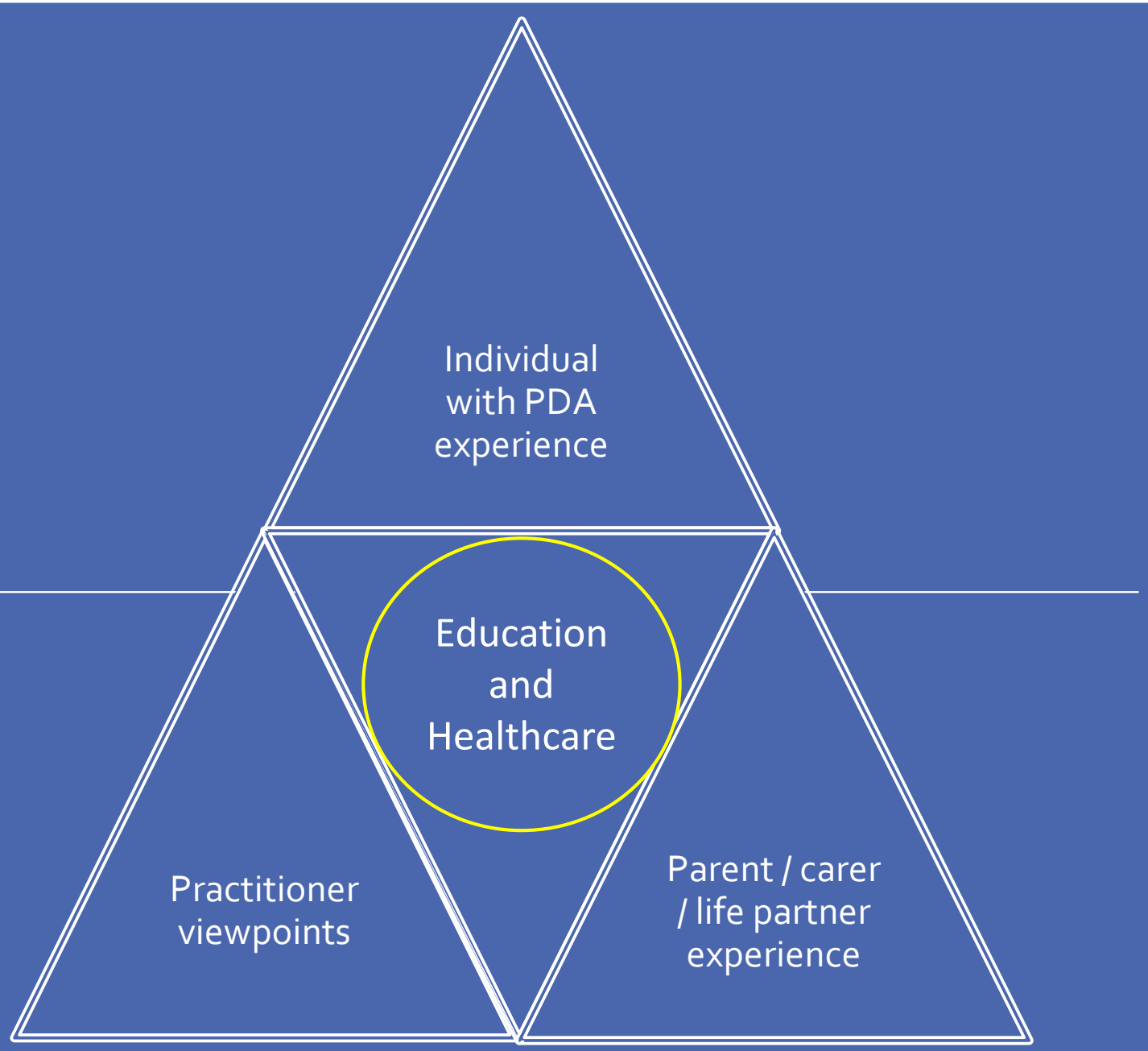
Mesosystem
Availability and uilisation of SNA support, school ethos, autism awareness-acceptance-understanding, IEPs, home-school communication, management of transitions school policies e.g. uniforms and homework, supported transitions, local provision and geographical restrictions, private or public healthcare

Microsystem
Feeling valued and accepted, opportunities to participate with peers, individualised approaches to facilitate achievement, relationships with peers, implementation of sensory diet, access to therapies, parental resources and input, idiosyncratic autism profile, dual exceptionality, availability of services and school placements

Chronosystem
Physiological, emotional and cognitive development; social and cultural thinking; economic booms and recessions; educational and medical approaches; research; activism

Impact events:
Changes in personal circumstances e.g. funding, housing; changes in / additions to autism diagnosis e.g. mental health; change in medication; changes in support teams e.g. new teachers, clinician; management of micro (between classes) and macro (between education placements) transitions, child services to adult services.


Issues of immediate practical concern
Services and supports (all stakeholder groups)
Knowledge about autism (autistic adults, parents, professionals)
Research logistics (researchers)
developing everyday skills (autistic adults, parents)
evidence-based services and interventions (autistic adults, parents, professionals, researchers)
post-diagnostic support (parents, professionals)
employment (autistic adults, parents)
practitioner training (autistic adults, parents, professionals)
accurate public awareness about autism (autistic adults, parents, professionals)


Individual with PDA experience
Education and Healthcare
Practitioner viewpoints
Parent / carer / life partner experience

Delphi consultation to determine evidence base

Working Group meetings: gather and scrutinize documents / evidence, discussion, inclusion and exclusion, summary and production.

Invited participants:

- Practitioners (SALT, OT, Educational and Clinical Psychologists, Teachers, Guidance Counsellors, Psychotherapists).
- Entities: NCSE, NEPS, PSI
- Parents
- Individuals with PDA / PDAers

Evidence Informed Advice

- Advice for parents, by parents
- Supporting children with PDA in Primary school settings
- Supporting Students with PDA in Post-Primary School Settings
- Supporting people with PDA in Higher and Further education and training.
- Supporting Children, Young people and Adults with PDA in Clinical settings
- Supporting people with PDA in Adult services

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Tommy's Story

Tommy is six years old and lives at home with his mother and grandparents. Tommy is lingustically very advanced for his age, although he did not begin to speak until the age of 18 months, when he did start speaking his language was very sophisticated. Tommy enrolled in a pre-school context at the age of 2 years but was removed from this setting after 3 months for violent behaviour towards the teacher. Tommy's mother then waited 10 months for a referral from the GP for an Assessment of Needs. Over the space of two months he received assessments by Speech and Language, Occupational Therapy, and an ADOS assessment conducted by a Psychologist. During this latter assessment Tommy became very agitated and sat under a chair screaming for the assessor to leave him alone. He received a diagnosis of Autism however due to his young age it was decided that he would be re-assessed for ADHD and ODD at the age of six years.

Tommy spent the next 12 months at home, prior to attending an ASD specific preschool from November 2017 until July 2019. He was assigned to the Early Intervention Team (EIT) at the age of 4 years however this interaction has been limited to meetings with the Specialist Nurse, as Tommy refused to engage with therapy. His mother was obliged to attend a parenting course. Due to continuing extreme violent and dangerous behaviour Tommy was referred for an assessment with CAMHS at the age of 5 years. Typical behaviours include smashing windows, attempting to exit a moving vehicle, destroying personal property including his own computing equipment and areas of the family home.

Six months after the referral his mother received a letter from the EIT stating that he had been removed from the waiting list as it was full. Tommy's mother later met with the Specialist Nurse and mentioned PDA, and soon afterwards received an appointment for a psychological assessment. At this meeting arrangements were made for a home and school visit but the EIT also informed Tommy's mother that they were discharging Tommy from their services because he was almost 6 years old and would no longer meet the criteria of early intervention: "So our early intervention was exactly no intervention at all."

Tommy's mother re-applied to CAMHS and was offered an emergency appointment on the strength of Tommy's behavioural challenges and he subsequently received a diagnosis of PDA. The assessment also observed that he would have benefitted from early intervention in the form of a sensory diet, CBT and occupational therapy, and access to a school environment specialising in challenging behaviour.

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Advice for Parents by Parents

- Diagnosis and presentation of PDA – An autism diagnosis is enough, another separates PDA assessment is not required

- NOT caused by parenting "styles" or "bad" parenting

- Appropriate approaches to interacting or supporting their child

- Parental support and need for advocacy for their child.

- Ways to prepare for assessment/ interactions with schools and awareness of rights and supports

Advice for Parents by Parents to Support Children and Adults with PDA

1 Any parent who feels that their child (born after 1st June 2002) may have a disability can apply for an Assessment of Need as stipulated under the Disability Act 2005. An application can also be made by a legal guardian or a personal advocate assigned by the Citizens Information Board. Apply:
https://www.hse.ie/eng/services/list/4/disability/disability-assessment/application-for-assessment-of-need-2017.pdf

2 When a parent discovers PDA either online at a course/ conference or through word of mouth it is usually a light bulb moment.

3 Your child is not bold, he/she is often in a highly anxious frame of mind which can be terrifying for them.

4 You are not a bad parent, in fact quite the opposite, you are an amazing parent. PDA requires a totally different style of parenting that you will question (and so will your friends, family and schools). While strategies suggested for PDA may appear totally different to the strategies more regularly recommended for Autistic Children, they often do work.

5 Seek support from other parents / peer support groups online and in person who have been / are going through some similar challenges with services/schools etc. They can be a great source of practical and emotional support.

6 PDA is a dimension of the autism profile and there are no separate diagnostic assessment instruments. You can consult with the team conducting the ASD diagnosis and ask them to explore this profile.

7 Request a 'hello and welcome' letter from the clinician prior to attending a first appointment. This should be addressed to the child, adolescent or adult with PDA and include an image of the setting, and a brief outline of what will happen.

8 If you feel your child needs mental health support, Consult the Child and Adolescent Mental Health Service (CAMHS) Standard Operating Procedures which provide information on their service procedures:
https://www.hse.ie/eng/services/list/4/mental-health-services/camhs/operational-guideline/

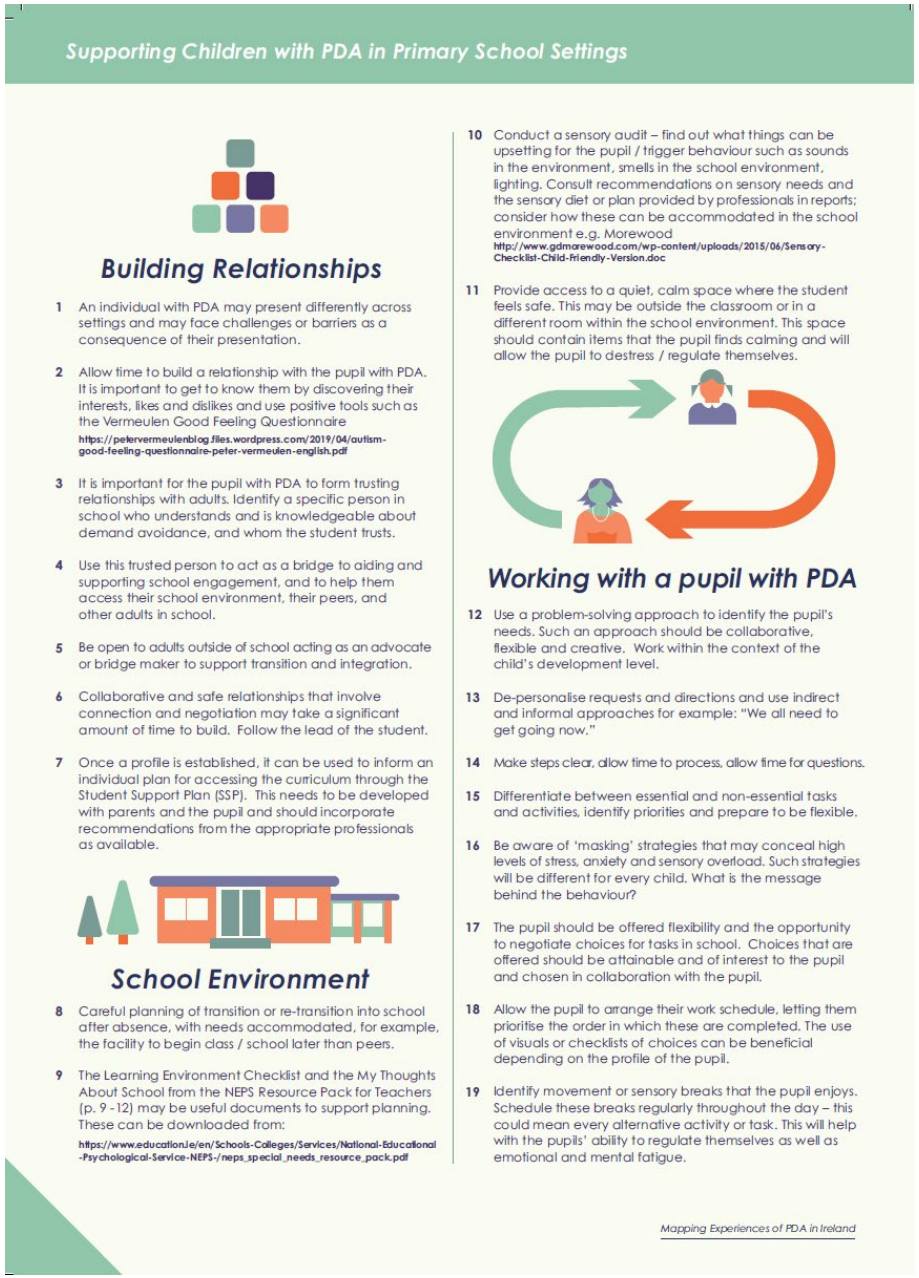
9 Create a brief profile of your child to take first meetings with clinicians or practitioners. You might find it helpful to complete the 'What PDA means to me' resource together
https://www.pdasociety.org.uk/files/download/c608f910bcf6f5

10 Identify a specific person in school who understands / is knowledgeable about demand avoidance, and whom your child trusts. DBS schools have a Home School Liaison Coordinator who can be a useful contact point and bridge between school /teaching staff and home.

Mapping Experiences of PDA in Ireland

Primary School settings

- Building Relationships
- School Environment
- Working with a pupil with PDA
- Communication



Supporting Children with PDA in Primary School Settings

Building Relationships

1 An individual with PDA may present differently across settings and may face challenges or barriers as a consequence of their presentation.

2 Allow time to build a relationship with the pupil with PDA. It is important to get to know them by discovering their interests, likes and dislikes and use positive tools such as the Vermeulen Good Feeling Questionnaire
https://petervermeulenblog.files.wordpress.com/2019/04/autism-good-feeling-questionnaire-peter-vermeulen-english.pdf

3 It is important for the pupil with PDA to form trusting relationships with adults. Identify a specific person in school who understands and is knowledgeable about demand avoidance, and whom the student trusts.

4 Use this trusted person to act as a bridge to aiding and supporting school engagement, and to help them access their school environment, their peers, and other adults in school.

5 Be open to adults outside of school acting as an advocate or bridge maker to support transition and integration.

6 Collaborative and safe relationships that involve connection and negotiation may take a significant amount of time to build. Follow the lead of the student.

7 Once a profile is established, it can be used to inform an individual plan for accessing the curriculum through the Student Support Plan (SSP). This needs to be developed with parents and the pupil and should incorporate recommendations from the appropriate professionals as available.

School Environment

8 Careful planning of transition or re-transition into school after absence, with needs accommodated, for example, the facility to begin class / school later than peers.

9 The Learning Environment Checklist and the My Thoughts About School from the NEPS Resource Pack for Teachers (p. 9 - 12) may be useful documents to support planning. These can be downloaded from:
https://www.education.ie/en/Schools-Colleges/Services/National-Educational-Psychological-Service-NEPS-/neps_special_needs_resource_pack.pdf

10 Conduct a sensory audit – find out what things can be upsetting for the pupil / trigger behaviour such as sounds in the environment, smells in the school environment, lighting. Consult recommendations on sensory needs and the sensory diet or plan provided by professionals in reports; consider how these can be accommodated in the school environment e.g. Morewood
http://www.gdmorewood.com/wp-content/uploads/2015/06/Sensory-Checklist-Child-Friendly-Version.doc

11 Provide access to a quiet, calm space where the student feels safe. This may be outside the classroom or in a different room within the school environment. This space should contain items that the pupil finds calming and will allow the pupil to destress / regulate themselves.

Working with a pupil with PDA

12 Use a problem-solving approach to identify the pupil's needs. Such an approach should be collaborative, flexible and creative. Work within the context of the child's development level.

13 De-personalise requests and directions and use indirect and informal approaches for example: "We all need to get going now."

14 Make steps clear, allow time to process, allow time for questions.

15 Differentiate between essential and non-essential tasks and activities, identify priorities and prepare to be flexible.

16 Be aware of 'masking' strategies that may conceal high levels of stress, anxiety and sensory overload. Such strategies will be different for every child. What is the message behind the behaviour?

17 The pupil should be offered flexibility and the opportunity to negotiate choices for tasks in school. Choices that are offered should be attainable and of interest to the pupil and chosen in collaboration with the pupil.

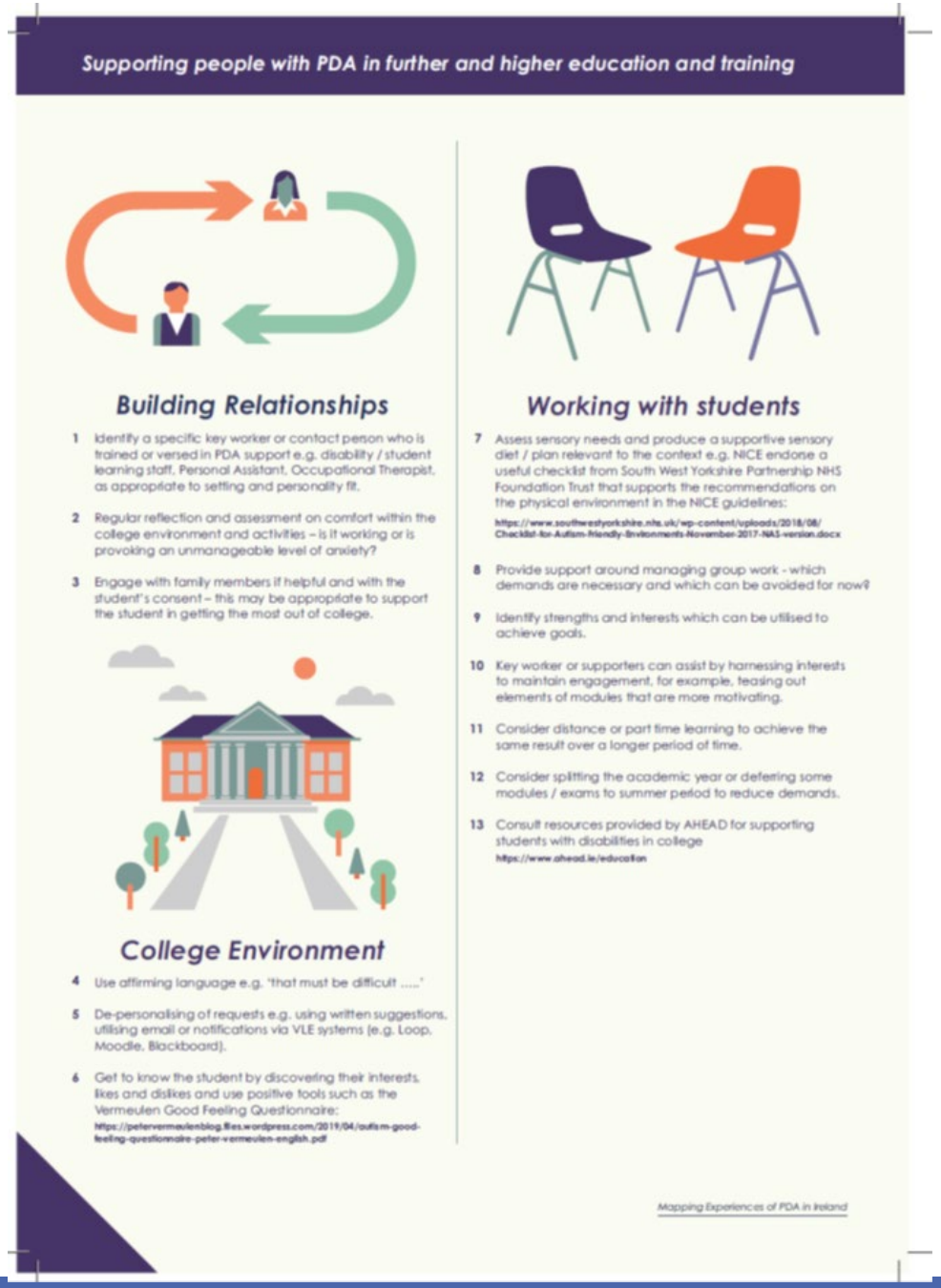
18 Allow the pupil to arrange their work schedule, letting them prioritise the order in which these are completed. The use of visuals or checklists of choices can be beneficial depending on the profile of the pupil.

19 Identify movement or sensory breaks that the pupil enjoys. Schedule these breaks regularly throughout the day – this could mean every alternative activity or task. This will help with the pupils' ability to regulate themselves as well as emotional and mental fatigue.

Mapping Experiences of PDA in Ireland

Post Primary School settings

- Building Relationships
- College Environment
- Working with students
- Communication



Supporting people with PDA in further and higher education and training

Building Relationships

1 Identify a specific key worker or contact person who is trained or versed in PDA support e.g. disability / student learning staff, Personal Assistant, Occupational Therapist, as appropriate to setting and personality fit.

2 Regular reflection and assessment on comfort within the college environment and activities – is it working or is provoking an unmanageable level of anxiety?

3 Engage with family members if helpful and with the student's consent – this may be appropriate to support the student in getting the most out of college.

College Environment

4 Use affirming language e.g. 'that must be difficult .....'

5 De-personalising of requests e.g. using written suggestions, utilising email or notifications via VLE systems (e.g. Loop, Moodle, Blackboard).

6 Get to know the student by discovering their interests, likes and dislikes and use positive tools such as the Vermeulen Good Feeling Questionnaire:
https://petervermeulenblog.files.wordpress.com/2019/04/autism-good-feeling-questionnaire-peter-vermeulen-english.pdf

Working with students

7 Assess sensory needs and produce a supportive sensory diet / plan relevant to the context e.g. NICE endorse a useful checklist from South West Yorkshire Partnership NHS Foundation Trust that supports the recommendations on the physical environment in the NICE guidelines:
https://www.southwestyorkshire.nhs.uk/wp-content/uploads/2018/08/Checklist-for-Autism-friendly-Environments-November-2017-NAS-version.docx

8 Provide support around managing group work - which demands are necessary and which can be avoided for now?

9 Identify strengths and interests which can be utilised to achieve goals.

10 Key worker or supporters can assist by harnessing interests to maintain engagement, for example, teasing out elements of modules that are more motivating.

11 Consider distance or part time learning to achieve the same result over a longer period of time.

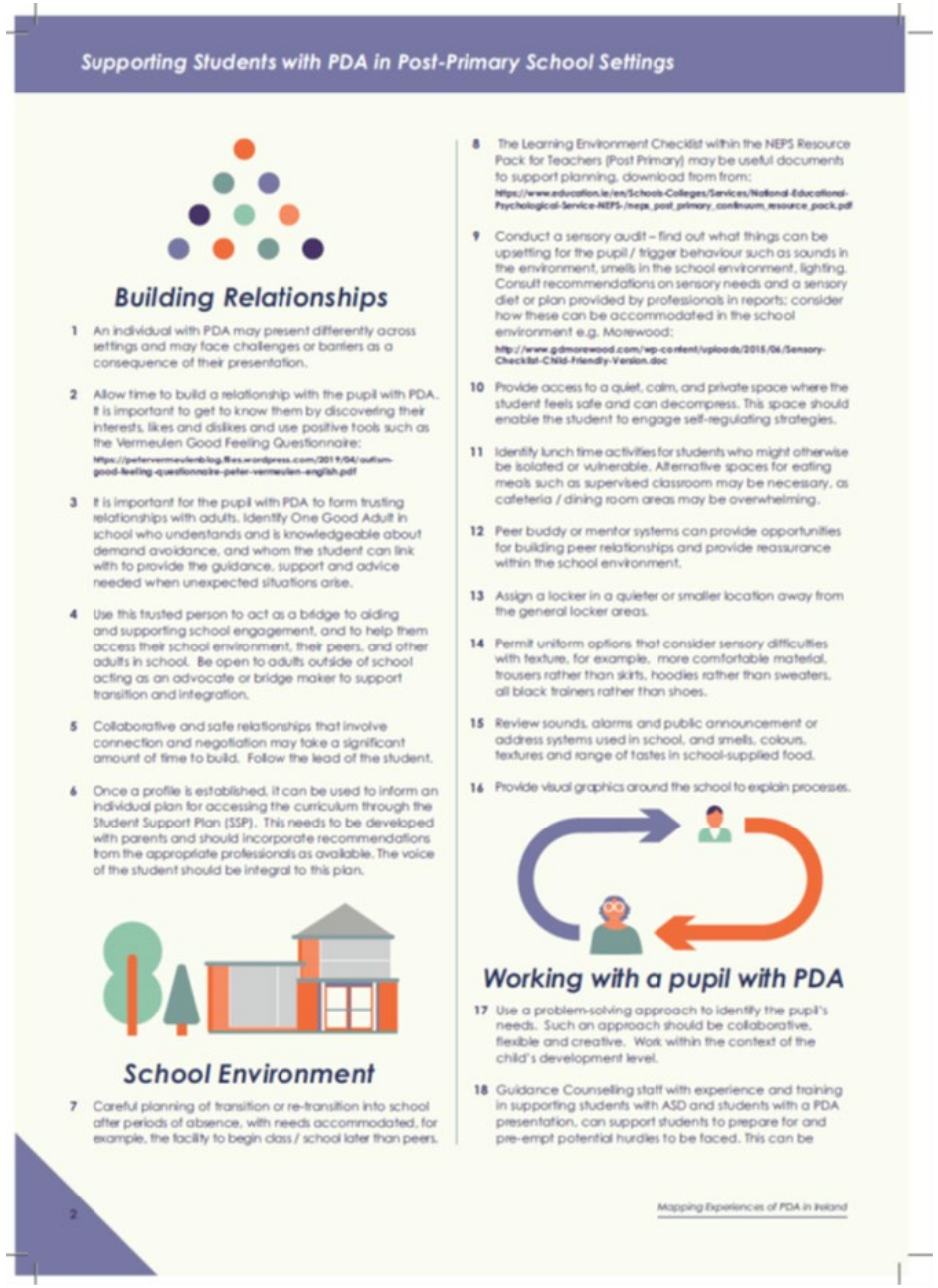
12 Consider splitting the academic year or deferring some modules / exams to summer period to reduce demands.

13 Consult resources provided by AHEAD for supporting students with disabilities in college
https://www.ahead.ie/education

Mapping Experiences of PDA in Ireland

Further/ Higher ed. and training

- Building Relationships
- School Environment
- Working with a students with PDA
- Universal Design for Learning
- Placement, internship and work experience



Supporting Students with PDA in Post-Primary School Settings

Building Relationships

1 An individual with PDA may present differently across settings and may face challenges or barriers as a consequence of their presentation.

2 Allow time to build a relationship with the pupil with PDA. It is important to get to know them by discovering their interests, likes and dislikes and use positive tools such as the Vermeulen Good Feeling Questionnaire:
https://petervermeulenblog.files.wordpress.com/2011/04/autism-good-feeling-questionnaire-peter-vermeulen-english.pdf

3 It is important for the pupil with PDA to form trusting relationships with adults. Identify One Good Adult in school who understands and is knowledgeable about demand avoidance, and whom the student can link with to provide the guidance, support and advice needed when unexpected situations arise.

4 Use this trusted person to act as a bridge to aiding and supporting school engagement, and to help them access their school environment, their peers, and other adults in school. Be open to adults outside of school acting as an advocate or bridge maker to support transition and integration.

5 Collaborative and safe relationships that involve connection and negotiation may take a significant amount of time to build. Follow the lead of the student.

6 Once a profile is established, it can be used to inform an individual plan for accessing the curriculum through the Student Support Plan (SSP). This needs to be developed with parents and should incorporate recommendations from the appropriate professionals as available. The voice of the student should be integral to this plan.

School Environment

7 Careful planning of transition or re-transition into school after periods of absence, with needs accommodated, for example, the facility to begin class / school later than peers.

8 The Learning Environment Checklist within the NEPS Resource Pack for Teachers (Post Primary) may be useful documents to support planning, download from from:
https://www.education.ie/en/Schools-Colleges/Services/National-Educational-Psychological-Service-NEPS-/neps_post_primary_continuum_resource_pack.pdf

9 Conduct a sensory audit – find out what things can be upsetting for the pupil / trigger behaviour such as sounds in the environment, smells in the school environment, lighting. Consult recommendations on sensory needs and a sensory diet or plan provided by professionals in reports; consider how these can be accommodated in the school environment e.g. Morewood:
http://www.gdmorewood.com/wp-content/uploads/2015/06/Sensory-Checklist-Child-Friendly-Version.doc

10 Provide access to a quiet, calm, and private space where the student feels safe and can decompress. This space should enable the student to engage self-regulating strategies.

11 Identify lunch time activities for students who might otherwise be isolated or vulnerable. Alternative spaces for eating meals such as supervised classroom may be necessary, as cafeteria / dining room areas may be overwhelming.

12 Peer buddy or mentor systems can provide opportunities for building peer relationships and provide reassurance within the school environment.

13 Assign a locker in a quieter or smaller location away from the general locker areas.

14 Permit uniform options that consider sensory difficulties with texture, for example, more comfortable material, trousers rather than skirts, hoodies rather than sweaters, all black trainers rather than shoes.

15 Review sounds, alarms and public announcement or address systems used in school, and smells, colours, textures and range of tastes in school-supplied food.

16 Provide visual graphics around the school to explain processes.

Working with a pupil with PDA

17 Use a problem-solving approach to identify the pupil's needs. Such an approach should be collaborative, flexible and creative. Work within the context of the child's development level.

18 Guidance Counselling staff with experience and training in supporting students with ASD and students with a PDA presentation, can support students to prepare for and pre-empt potential hurdles to be faced. This can be

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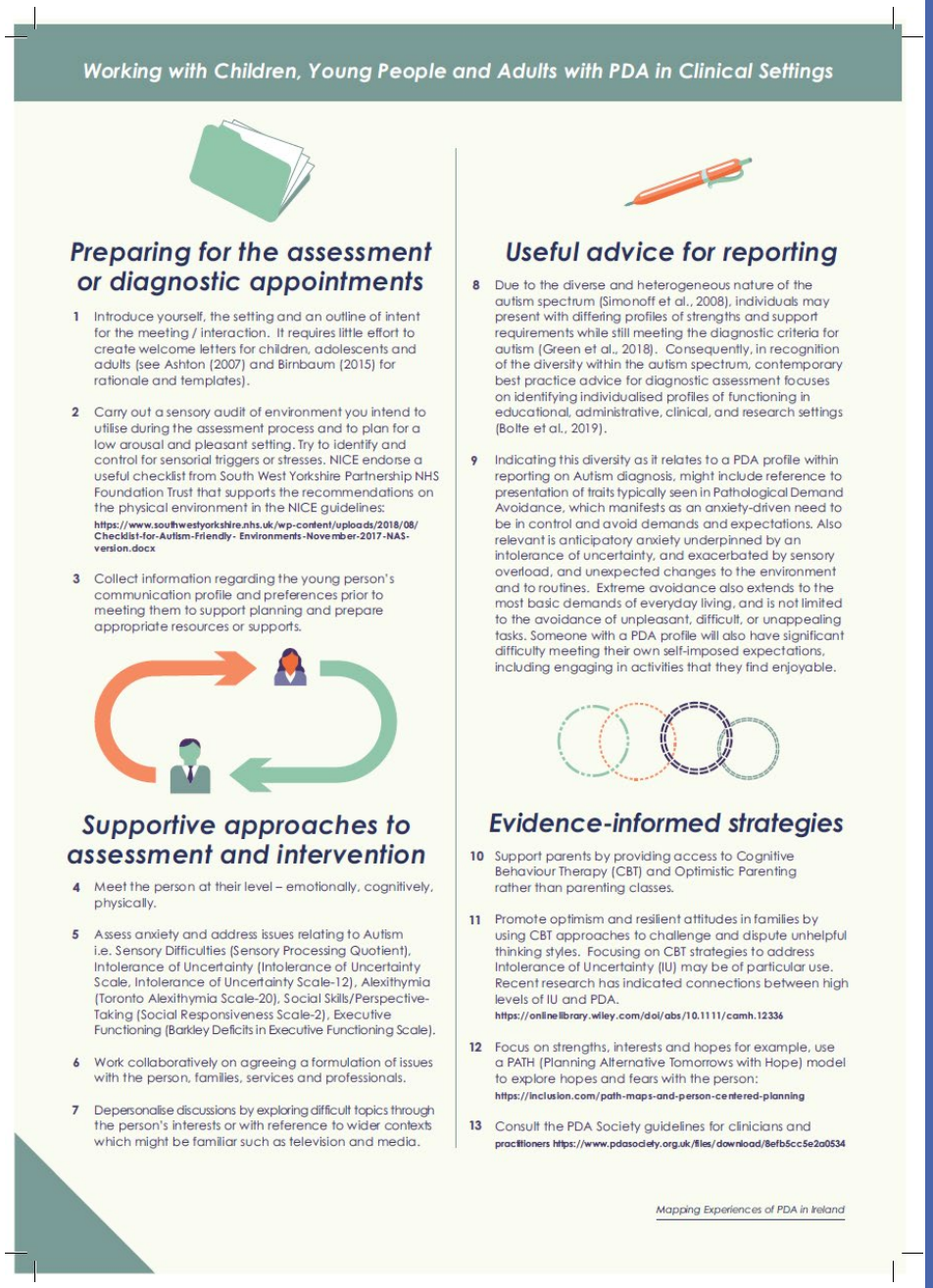
Mapping Experiences of PDA in Ireland

Supporting PDA in Clinical Settings

- Preparing for the assessment/ Diagnostic appointment
- Supportive approaches to assessment
- Useful advice for reporting
- Evidence-Informed strategies



Working with Children, Young People and Adults with PDA in Clinical Settings

Preparing for the assessment or diagnostic appointments

1 Introduce yourself, the setting and an outline of intent for the meeting / interaction. It requires little effort to create welcome letters for children, adolescents and adults (see Ashton (2007) and Birnbaum (2015) for rationale and templates).

2 Carry out a sensory audit of environment you intend to utilise during the assessment process and to plan for a low arousal and pleasant setting. Try to identify and control for sensorial triggers or stresses. NICE endorse a useful checklist from South West Yorkshire Partnership NHS Foundation Trust that supports the recommendations on the physical environment in the NICE guidelines:
https://www.southwestyorkshire.nhs.uk/wp-content/uploads/2018/08/Checklist-for-Autism-Friendly- Environments-November-2017-NAS-version.docx

3 Collect information regarding the young person's communication profile and preferences prior to meeting them to support planning and prepare appropriate resources or supports.

Supportive approaches to assessment and intervention

4 Meet the person at their level – emotionally, cognitively, physically.

5 Assess anxiety and address issues relating to Autism i.e. Sensory Difficulties (Sensory Processing Quotient), Intolerance of Uncertainty (Intolerance of Uncertainty Scale, Intolerance of Uncertainty Scale-12), Alexithymia (Toronto Alexithymia Scale-20), Social Skills/Perspective-Taking (Social Responsiveness Scale-2), Executive Functioning (Barkley Deficits in Executive Functioning Scale).

6 Work collaboratively on agreeing a formulation of issues with the person, families, services and professionals.

7 Depersonalise discussions by exploring difficult topics through the person's interests or with reference to wider contexts which might be familiar such as television and media.

Useful advice for reporting

8 Due to the diverse and heterogeneous nature of the autism spectrum (Simonoff et al., 2008), individuals may present with differing profiles of strengths and support requirements while still meeting the diagnostic criteria for autism (Green et al., 2018). Consequently, in recognition of the diversity within the autism spectrum, contemporary best practice advice for diagnostic assessment focuses on identifying individualised profiles of functioning in educational, administrative, clinical, and research settings (Bolte et al., 2019).

9 Indicating this diversity as it relates to a PDA profile within reporting on Autism diagnosis, might include reference to presentation of traits typically seen in Pathological Demand Avoidance, which manifests as an anxiety-driven need to be in control and avoid demands and expectations. Also relevant is anticipatory anxiety underpinned by an intolerance of uncertainty, and exacerbated by sensory overload, and unexpected changes to the environment and to routines. Extreme avoidance also extends to the most basic demands of everyday living, and is not limited to the avoidance of unpleasant, difficult, or unappealing tasks. Someone with a PDA profile will also have significant difficulty meeting their own self-imposed expectations, including engaging in activities that they find enjoyable.

Evidence-informed strategies

10 Support parents by providing access to Cognitive Behaviour Therapy (CBT) and Optimistic Parenting rather than parenting classes.

11 Promote optimism and resilient attitudes in families by using CBT approaches to challenge and dispute unhelpful thinking styles. Focusing on CBT strategies to address Intolerance of Uncertainty (IU) may be of particular use. Recent research has indicated connections between high levels of IU and PDA.
https://onlinelibrary.wiley.com/doi/abs/10.1111/camh.12336

12 Focus on strengths, interests and hopes for example, use a PATH (Planning Alternative Tomorrows with Hope) model to explore hopes and fears with the person:
https://inclusion.com/path-maps-and-person-centered-planning

13 Consult the PDA Society guidelines for clinicians and practitioners **https://www.pdasociety.org.uk/files/download/8efb5cc5e2a0534**

Mapping Experiences of PDA in Ireland

Supporting PDA in Adults Services

- Building Relationships
- Communication
- Working with the person
- Collaboration

Supporting Individuals with PDA in Adult Services: Clinicians and Practitioners

Building Relationships

1 Introduce yourself, the setting and an outline of intent for the meeting / interaction. It requires little effort to create welcome letters for children, adolescents and adults (see Ashton (2007) and Birnbaum (2015) for rationale and templates).

2 Provide collaborative and safe relationships that involve connection and negotiation. It may take a significant amount of time to build this relationship. Follow the lead of the person. Be interested in them and particularly their interests.

3 Meet the person at their level – emotionally, cognitively, physically.

4 Reflect on what works/doesn't work in meeting the person. Consult with the person. Integrate Feedback Informed Treatment (FIT) approaches to develop a 'culture of feedback' with the person and encourage collaboration. The Session Rating Scale (SRS) form can be used to elicit feedback to support this process (Miller et al., 2016).

Communication

5 Use affirming language e.g. 'that must be difficult for you ...'

6 Use externalisation to discuss issues or problems that arise i.e. as external to the person. For example, 'How does anxiety sneak up on you?' This approach can also be used with families. 'How does anxiety affect the family in the morning?' This approach aims to reduce blame and increase collaboration.
https://dulwichcentre.com.au/articles-about-narrative-therapy/externalising/

7 When discussing ideas/concepts relating to areas that may be difficult, 'plant seeds' by introducing a topic briefly, and move on to another subject immediately. Wait for the person to revisit the original topic, or come back to it later.

8 Depersonalise discussions by discussing difficult topics through the person's interests or other means. For example, exploring the connections between emotions, thoughts, behaviours, relationships and different points of views of people in movies, TV shows, computer games or history.

Working with the Person

9 Use problem-solving to help the person think through their options to respond to particular difficulties they are experiencing rather than immediately giving advice. Ask if your advice could be added to the problem-solving process after the person has suggested their own options
https://www.gatewayhelp.co.uk/docs/ProblemSolvingWorksheet.pdf

10 Be conscious that there are three problem-solving approaches. Plan A (solving a problem unilaterally), Plan B (solving a problem collaboratively) and Plan C setting the problem aside for now). Be conscious of which approach you are using at each stage of working with the person. Collaborative Problem-solving and Proactive Solutions (CPS-PS) although initially developed for working with children, can be a useful approach.
https://www.livesinthebalance.org/about-cps

11 Assess anxiety and address issues relating to ASD i.e. Sensory Difficulties (Sensory Processing Quotient; Tavasolli et al., 2014), Intolerance of Uncertainty (Intolerance of Uncertainty Scale-12; Carleton et al., 2007), Alexithymia (Toronto Alexithymia Scale-20; Bagby et al., 1994), Social Skills/Perspective-Taking (Social Responsiveness Scale-2; Constantino and Gruber, 2012), Executive Functioning (Barkley Deficits in Executive Functioning Scale; Barkley, 2011). Consider how these issues may be part of a formulation of the issues experienced by the person.

12 Adapted CBT for ASD is currently recommended (**NICE Guidelines**) for individuals with ASD who experience anxiety. These include education around labelling emotions, using a more concrete approach, using visuals (e.g. thought bubbles and thermometers) and writing (using a whiteboard), offering breaks to maintain attention if necessary and integrating the person's special interest into sessions. Focusing on CBT strategies to address Intolerance of Uncertainty may be of particular use. Recent research has indicated connections between high levels of Intolerance of Uncertainty and PDA (Stuart et al., 2019).

13 Promote self-regulation/co-regulation/resilience and interpersonal effectiveness skills through supporting the identification of emotions/regulation states, triggers, strategies, reflection and planning. Dialectical Behaviour Therapy (DBT) includes a curriculum for developing an understanding and managing emotions and interpersonal effectiveness (Linehan, 2015).

14 Focus on strengths, interests and hopes. For example, use a PATH (Planning Alternative Tomorrows with Hope) model to explore hopes and fears with the person
https://inclusion.com/path-maps-and-person-centered-planning/
Similarly, using solution-focused strategies can be useful in exploring these areas (Bavelas et al., 2013).

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Tommy's Story

Tommy is six years old and lives at home with his mother and grandparents. Tommy is lingustically very advanced for his age, although he did not begin to speak until the age of 18 months, when he did start speaking his language was very sophisticated. Tommy enrolled in a pre-school context at the age of 2 years but was removed from this setting after 3 months for violent behaviour towards the teacher. Tommy's mother then waited 10 months for a referral from the GP for an Assessment of Needs. Over the space of two months he received assessments by Speech and Language, Occupational Therapy, and an ADOS assessment conducted by a Psychologist. During this latter assessment Tommy became very agitated and sat under a chair screaming for the assessor to leave him alone. He received a diagnosis of Autism however due to his young age it was decided that he would be re-assessed for ADHD and ODD at the age of six years.

Tommy spent the next 12 months at home, prior to attending an ASD specific preschool from November 2017 until July 2019. He was assigned to the Early Intervention Team (EIT) at the age of 4 years however this interaction has been limited to meetings with the Specialist Nurse, as Tommy refused to engage with therapy. His mother was obliged to attend a parenting course. Due to continuing extreme violent and dangerous behaviour Tommy was referred for an assessment with CAMHS at the age of 5 years. Typical behaviours include smashing windows, attempting to exit a moving vehicle, destroying personal property including his own computing equipment and areas of the family home.

Six months after the referral his mother received a letter from the EIT stating that he had been removed from the waiting list as it was full. Tommy's mother later met with the Specialist Nurse and mentioned PDA, and soon afterwards received an appointment for a psychological assessment. At this meeting arrangements were made for a home and school visit but the EIT also informed Tommy's mother that they were discharging Tommy from their services because he was almost 6 years old and would no longer meet the criteria of early intervention: "So our early intervention was exactly no intervention at all."

Tommy's mother re-applied to CAMHS and was offered an emergency appointment on the strength of Tommy's behavioural challenges and he subsequently received a diagnosis of PDA. The assessment also observed that he would have benefitted from early intervention in the form of a sensory diet, CBT and occupational therapy, and access to a school environment specialising in challenging behaviour.

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No access to education, services, supports. Watching the preventable decline of my child in constant anger, melt downs, violence, negativity, inappropriate behaviour, depression and anxiety. Not a having a life. Feeling helpless.

My son is about to go to secondary school, I'm going to give it my absolute best shot, but, I'd be fairly confident it's not, actually going to work at all, and, so, lots of people say, you know, what's your plan B? And look, I just don't have one.

Thank you

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Dr Alison Doyle
00353877426260
alison.doyle@dcu.ie

Dr Neil Kenny
neil.kenny@dcu.ie

Dr Sinead McNally
sinead.mcnally@dcu.ie

Thank you!

DCU Institiúid Oideachais Institute of Education

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