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Adults living with a diagnosis of ADHD or ASD: Different diagnoses, yet similar personal impact?

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Disclosure

¹Irene P. Walsh, PhD. & ²Orla Breen, BSc. & ³Sheafra Doyle, BSc.

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- ¹Employed at Trinity College Dublin (TCD) Ireland
- TCD part funded the research and my travel here (conference allowance)
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- We received no financial gain from this research or this presentation
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Aim

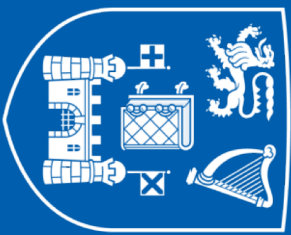
1. To provide greater insight into the phenomenon of living with ADHD and/or ASD in adulthood, **as directly reported** by those who experience the conditions.
2. To explore how a **late diagnosis, attitudes of others, and social communication challenges** may impact sense of self, wellbeing, and identity.



Rationale

1. Being **diagnosed** with - and **experiencing** - ADHD and/or ASD in adulthood can have a **marked impact** on many aspects of a person's life, including social communication (*Punshon, Skirrow, & Murphy, 2009; Schrevel et al., 2016; Walsh, Delmar & Jago, 2018*).
2. Adult lived experiences of ADHD and/or ASD **under-researched** when compared with childhood experiences
3. **In-depth analysis of first-person accounts** may render some insights into what these diagnoses might mean for an individual in their adult years, and particularly when diagnosed in adulthood.





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Method

Data merge X 2 projects


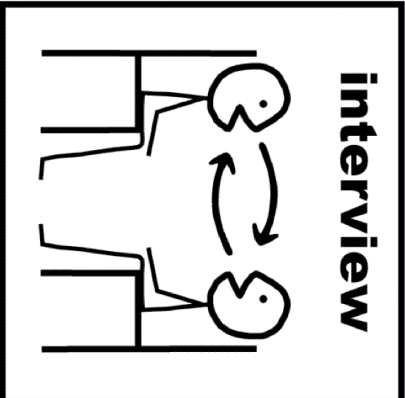
People / Number	Data	Criteria for inclusion	Format
<p>People with adult diagnosed ADHD</p> <p>n=6</p>	<ul style="list-style-type: none"> blogs from https://themighty.com self-reported experiences of living with ADHD in adulthood, including late diagnosis 	<ol style="list-style-type: none"> ADHD primary topic recency of post (Mar 2016-Sept 2017) single author length (>500 words) 	
<p>People with adult-diagnosed ASD</p> <p>n=4</p>	<ul style="list-style-type: none"> *in-depth interviews self-reported experiences of living with ASD in adulthood, including late diagnosis <p>* approved by the Research Ethics Committee of host School at TCD</p>	<ol style="list-style-type: none"> diagnosis beyond age 18 years absence of ID proficient verbal abilities to participate in interview 	



Table 2.1 Details of the Sample

Title	Account Number	Participant	Word Count	Date Published	Link
When I Was Diagnosed with ADHD as an Adult	1	Mattijs	830	07/03/2016	https://themighty.com/2016/03/getting-diagnosed-with-adhd-as-an-adult/
An Experiment for People Who Don't Understand ADHD	2	Dee	842	23/06/2016	https://themighty.com/2016/06/whats-its-like-to-have-adhd-as-an-adult/
'But You're Too Smart to Have ADHD'	3	Kathleen	971	04/09/2017	https://themighty.com/2016/09/response-to-youre-too-smart-to-have-adhd/
What My ADHD Looks Like	4a	Jessica	800	01/02/2017	https://themighty.com/2017/02/what-adhd-looks-like/
I'm Not Inconsiderate, I Have ADHD	4b	Jessica	759	22/08/2017	https://themighty.com/2017/08/inconsiderate-rude-adhd/
When Socializing Is Exhausting for Someone with ADHD and Anxiety	5	Lissa	570	18/03/2017	https://themighty.com/2017/03/why-being-social-is-exhausting-for-me-as-someone-with-adhd-and-anxiety/
When a Friend Said, 'He Is So ADHD!'	6	Bradley	504	17/07/2017	https://themighty.com/2017/07/responding-to-hurtful-comments-about-adhd/

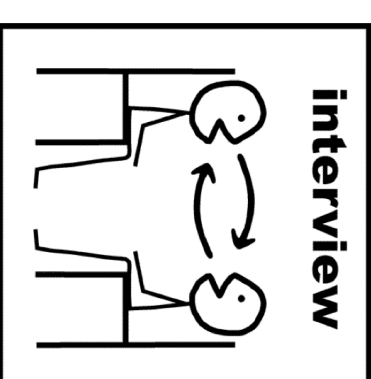


Interview Participants with ASD

Table 2.1: Participant Profile

Participant Name*	Theresa	Alex	Ben	Kevin
Gender	Female	Female	Male	Male
Age when diagnosis was received	42	19	18	23
Diagnosis: (Autism Spectrum Disorder or Asperger's Syndrome)	Asperger's Syndrome	High Functioning Autism	Asperger's Syndrome	High Functioning Autism
Previous/ Current Occupation	Clerical Worker	Student	Computer Programmer	Media Technician

*Pseudonyms used for all participants.



Analytic Methodology: Interpretative Phenomenological Analysis (IPA)

- **Phenomenon**=experience of ASD or ADHD
- **“Describe, understand and interpret** participants’ experiences” (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013).
- “Access to experience is always dependent on **what participants tell us** about that experience, and that the researcher then needs to **interpret** that account from the participant **in order to understand** their **experience** (Smith, Flowers, & Larkin, 2009).

Stage	Description
Stage 1	<ul style="list-style-type: none">• Active Engagement with data• Bracketing of preconceptions
Stage 2	<ul style="list-style-type: none">• Notes on descriptive, linguistic and conceptual features• Notes must be directly linked to data
Stage 3	<ul style="list-style-type: none">• Emergent themes identified
Stage 4	<ul style="list-style-type: none">• Super-ordinate themes identified
Stage 5	<ul style="list-style-type: none">• Initial four stages used for all other data sets
Stage 6	<ul style="list-style-type: none">• Formation of master themes

Sample analysis: ADHD data

What My ADHD Looks Like

Link: <https://themighty.com/2017/02/what-adhd-looks-like/>

Date published: February 1st, 2017

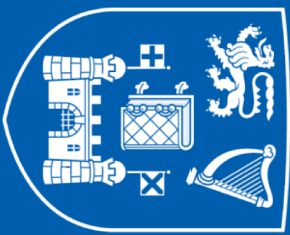
Account Number: 4a

Written by: Jessica



Line Nos.	Original text	Exploratory Comments			Emergent Themes
		Descriptive Comments	Linguistic Comments	Conceptual Comments	
1	I once read, "If you've met one person with ADHD, then you've met <i>one</i> person with ADHD." I think this is pretty accurate. ADHD is not a one-size-fits-all disorder, and in fact, it is pretty complex. It requires a multifaceted diagnostic approach, and its presentation can vary from person to person.	She has read that if you meet one person with ADHD then you met <i>one</i> person with ADHD.	Use of quotation to emphasise point that individuals with ADHD are not the same. Italics used on ' <i>one</i> ' to emphasise this point.	ADHD is heterogeneous.	ADHD is a heterogeneous condition.
2					
3					
4					
5					
6					
7					
8	I have heard many people with ADHD say that in order to focus, they need complete silence.	She has heard that some people with ADHD need silence to focus.			
9					
10	Background noises are too much of a distraction to concentrate. However, I am the opposite.	She needs background noise to focus. She has noise in the background	Italic on ' <i>need</i> ' to emphasise the extent of how much she needs background noise to concentrate.	She has heard opinions about how people with ADHD focus. Were these personal correspondents?	
11					
12	I <i>need</i> background noise. When I am doing			She needs background noise to focus.	Difficulties staying focused.





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Findings:

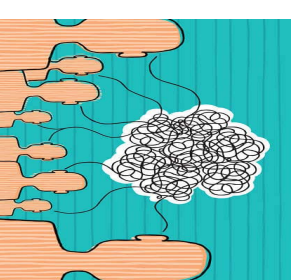
Common themes from data merge

Common Themes: ADHD & ASD

1. Diagnosis & Identity



2. Communication Challenges



3. Attitudes of others



Theme 1 : Diagnosis & Identity

Refers to how getting a diagnosis in adulthood impacted or affected sense of self or identity; included references to life before and after diagnosis



Theme 1: Diagnosis & Identity - ADHD

Dee	My fight was not with a man or external factors, but with my own mind. It's like I was constantly digging in a sand pit to find the real me. (L1-5)
Mattijs	The combination of treatment, medication, changes at work and working hard to find a better way of life should result in exactly that: a better life! I want to be more... me! And with the support of the people I love, I can (L97-105)
Kathleen	I'm the inattentive type (which often goes <u>undiagnosed</u> for longer). I have always assumed I had ADHD, but I was only diagnosed and put on medication four months ago. I am a junior at a four-year university, and I am majoring in nursing. Yes, I am in college. Yes, nursing is a hard major. Yes, I get good grades. Yes, I do have ADHD. (L12-19)
Jessica	I've learned not to be so hard on myself and to let go of some of the unrealistic expectations I had of myself. I've learned to discover and harness some amazing qualities, and I am continually finding new ways to manage the qualities that are not-so-amazing. I am an eternal work-in-progress, and it delights me to feel that I am always becoming a better version of me. (L58-72)

Theme 1: Diagnosis & Identity – ASD

Ben	<p>“I - It explains why I am the way I am, but I don’t LIVE myself by it. I don’t live by my diagnosis” (line, 288)</p> <p>“It’s an explanation of WHY I am who I am. Not WHO I am” (line, 354)</p>
Theresa	<p>“I DON’T consider myself (.) like I’m a person with Autism, NOT. em. It doesn’t define me ” (line 388)</p>
Kevin	<p>“It’s it’s a part of your personality and who you are, not everything about it is a negative thing. Like the social interaction stuff can be learned.</p>

Theme 2: Communication Challenges

Refers to a myriad of communication difficulties as reported, including:

- Small talk / banter
- To and fro' of conversation
- Remaining focused in conversation
- Engaging in social interactions
- Spontaneity
- Figurative language



Theme 2: Communication Challenges -ADHD

Mattijs	<p>Sorry. I really was interested the last time we spoke each other. I really tried to listen to what you were telling me. The thing is, I also participated in all the other conversations in the room, just not out loud. I apologize. I didn't realize I left you in the middle of our conversation and started a discussion with someone else. I was already speaking to her, wasn't I? Wait... that was in my head, not out loud. (L1-10)</p>
Lissa	<p>Here's how things typically go for me: I confidently start to engage in a conversation. I think about if I'm doing a good job. I have a song I haven't heard in years playing in my head. I can't remember if I unplugged the curling iron. What do I do with my face? Do I look bored? Where should I put my hands? Is my laugh gonna sound fake? I probably look so uninterested. Crap, they stopped talking. How do I respond? What did they even say? That song is still playing in my head. I need to make a grocery list when I get home...(L27-38)</p>
Jessica	<p>I really do want to hear what you have to say. I know you are talking to me, and I know it is important to you, and I desperately want to be able to hang on to your every word... but there is another conversation going on between the couple three tables over, and I don't see one, but I most certainly hear a baby crying somewhere around here. And that phone just won't stop ringing! I swear I just absorb the energy within my environment and it can get really overwhelming sometimes. I like to compare it to listening to multiple different radio stations at once at a high decibel, while trying to learn the lyrics to one song. Not easy. (L25-38)</p>

Theme 2: Communication Challenges - ASD

Theresa	...I'm still me with the, struggle socially (.) the diagnosis won't CURE IT, but it'll just, help it. (.) (L398) It helps me understand my, understand people (.) aw yeah. When they talk to me, my inability sometimes to have words IN THE MOMENT (.) Y' know? (L404)
Alex	And at that point then I didn't really KNOW how to, interact properly with people. (L122) Yeah em, sort of like you're about to fall asleep and you realise, {claps hands} "THAT'S what they meant!" [laugh].(L114)
Ben	Like I never had difficulty finding friends. I was just (.) what would it have been? It was NOT having a filter. (L96)
Kevin	The thing is something it's, it's hard for me to know how people interacting can be (.) just so NATURAL and easy. And then it must be hard for others to think how can he NOT? (L272)

Theme 3: Attitudes of others

Refers to how attitudes of others impacted or affected the person or person's perception of self, in the past or in the present



Theme 3: Attitude of others -ADHD

Kathleen	When they tell me I'm lazy or tell me to just focus they don't see how much it hurts. They don't see that I am already beating myself up on the inside. They don't see me frustrated and crying for losing everything all the time. They don't see me yelling at my brain to just read the darn page and stop listening to the girl tapping her shoe (L93-99)
Mattijs	Most of the time I don't like myself, and I'm terrified that you feel the same. (L42-43)
Lissa	Growing up, I was described as a lot of things — scatterbrained, a space cadet, quiet, bitchy, aloof, awkward, standoffish...It added up, and I was ashamed of what I felt was my flawed personality, constantly thinking there was something “wrong” with me but I couldn't control it. (L1-7)

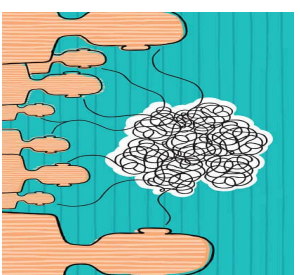


Theme 3: Attitude of others -ASD

Ben	<p>It's not about finding the help I – It's just “make my son be normal!” as opposed to “How do we help our son” (L412)</p>
Kevin	<p>It's still hard not to compare myself to others who are further on, and it's even HARDER when people kinda look down on you. Like I remember years ago someone said to me get a JOB, so It's like I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going mad. It's kind of insulting (L286)</p>
Alex	<p>And in college there are so many people that have autism, and everybody is SO much more AWARE of it, em, and so much more informed of it, it's not even something I really even say to people. (L394)</p>



Discussion 1



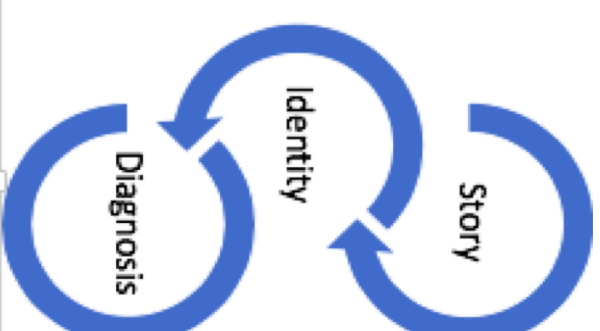
- 1. Common themes of: Diagnosis-Identity; communication; others' attitudes**
 - Commonalities across data- surprising?
- 2. Significance of late (adult) diagnosis**
 - Was welcomed; helped 'explain' or 'make sense of' past, often painful and perplexing experiences
- 3. Lived experience v 'living' experience**
 - Tendency to focus on the 'lived experience' as if 'over' or in the past is not useful and not true to nature of accounts
 - Analysis shows that such experiences are ongoing for individuals, that is in every moment of every day, when alone or 'in the spotlight' when in interaction with others, and as perceived by them

Discussion 2

4. People come to services with

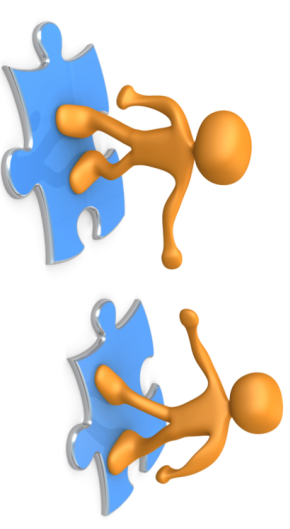
- a **story** to be heard
- an **identity**
- a **diagnosis**

As SLPs / healthcare professionals we must :



- listen to and hear those **stories** if we are to authentically support individuals
- must recognise that individuals have an ever-evolving **identity**, influenced by past and present experiences, with others' attitudes playing a part and impacting communication in different but similarly challenging ways
- should not underestimate the experience of a **diagnosis** and the way that diagnosis may be uniquely experienced by the individual, with its impact on self worth and identity

Discussion 3



5. Engagement with individuals

- “Over time, with the right conversations and relationships, we will be able to **engage better** with our clinical and research partners not merely as patients but as people working synergistically together within a community of health care” (*Hovey 2018 ; 63*)
- Such conversations with persons living with any health conditions, are fundamental to a **person-centered relational process** (*Hovey & Craig, 2011; Hovey, Rodriguez, Jordan & Morck, 2016*)
or
- a **‘person-anchored’ relational process** (*Walsh, Kovarsky, Mahler, Taylor-Champplin & O’Neill, 2018*), where not only the person, but the perception and understanding of others can influence therapeutic outcomes

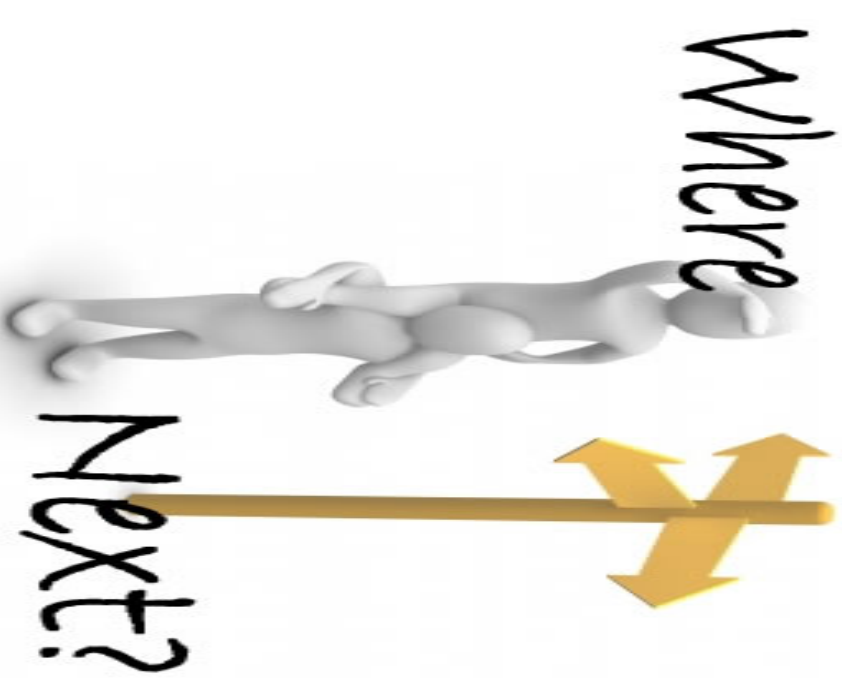
Clinical Implications: SLP

Aim to:

Develop person-centered, ecologically-driven, realistically-designed and authentically-tailored interventions for clients attending SLP services

Pay deliberate, explicit attention to personal impact of diagnosis and its effect on communication

Facilitate enhanced communication interactions by better understanding reported experiences that are not just 'lived' but 'living' in every moment of every day



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Conclusion

“The world and man [human-beings] are accessible through two kinds of investigations, in the first case explanatory [scientific] and in the second case reflective [philosophical]” Merleau-Ponty (1962) (p. 497)

We have shown that ‘reflective’ [philosophical] accounts can not only add to, but greatly enhance the ‘explanatory [scientific]’ accounts in textbooks, where often the person at the core of the ‘living experience’ is at risk of being inadvertently lost or perhaps viewed as a homogenous being, not unique in his/her own right.

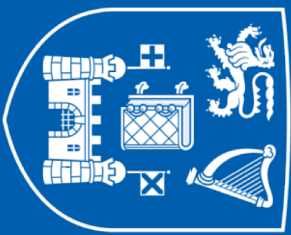
“nothing about me without me”

(Hovey et al., 2011).



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Thank You

Some references

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