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Neurodiversity assessments - the views of children and young people

Disclaimer: This evidence summary includes relevant literature identified from searches on the above topic, it is not an exhaustive list, it presents key finding and not recommendations for practice. This report also includes some personal reflections based around what was and wasn't found, these are clearly marked.

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Neurodiversity diagnosis – benefits and risks

Please note I didn't do a search for this, the information below is based on a previous search I completed and further information I came across during the process of searching for the other questions.

There are numerous studies that highlight the need for a diagnosis, the benefits of receiving a timely diagnosis and the risks associated with failed or delayed

diagnosis. Benefits included access to support / interventions, validation, easier to advocate for themselves, improved skills / behaviours, reasonable adjustments, understanding, improved prognosis, and improved quality of life. Risks of delayed diagnosis included numerous detrimental mental health, physical health and social outcomes.[1–7] For more information on these please see the 'focus on neurodevelopment' report.

One article discusses how an ADHD diagnosis may not always result in positive outcomes for some children and highlights potential negative outcomes of receiving a diagnosis for these children. Harmful outcomes of diagnosis included perceptions of decreased ability to change and loss of control, self-fulfilling prophecy of failure, increased stigma, isolation, and exclusion. However, they did state further research was needed. It was suggested stepped treatment and inclusive learning environments can be beneficial for all children, catering to a continuum of behavioural needs. Regardless of diagnosis, all children with behaviours inhibiting their potential should be supported with effective interventions. They suggest a tiered diagnostic process where those with severe / impairing symptoms are prioritised for assessment.[8]

Are children accepting of neurodiversity?

The research indicates there is still a lot of stigma around neurodiversity. Many studies mention children and young people facing stigma, discrimination, judgements, and bullying because of their autism / ADHD or the behaviours they exhibit due to those conditions.[9–11]

One study found having an autistic peer support group may reduce neurotypical stigma towards autistic pupils, if the visibility and activities of the peer support group increase knowledge and acceptance among neurotypical pupils, or if the inclusive approach of the group results in increased positive contact between neurotypical and neurodivergent pupils.[11]

Another study highlights the negative perceptions of autistic children by their peers. They found primary school children showed more negative implicit attitudes towards autistic children. Specifically, children were faster to spontaneously avoid autistic children and approach typically developing children than the reverse. Explicit negative attitudes towards autistic children did decrease as children got older, however, implicit attitudes remained constant.[12]

How do young people feel about autism and their diagnosis?

Research highlights young people's experiences following an autism diagnosis:

- Reluctant to disclose [9]
- Improve inclusion and support.[9]
- Potential discrimination, stigma, and prejudgements [9–11]
- Helped some young autistic people understand themselves and their current and previous behaviours / experiences [10]
- Some discontinuation of bullying [10]
- Taking time to accept the diagnosis / avoiding it [10]
- Opportunities to access specialised autism services [10]
- Aligning their identity as autistic or not autistic was better for developing more positive self-concepts than aligning to neither group [13]
- Some viewed having autism a burden / hardship [14]

Autistic identity

Many studies identify there is still stigma and discrimination / bullying of people who present as neurodiverse.[9–11] There is evidence that the way autistic young people view themselves and their identity, and connections with the autistic community impact on the young persons' well-being. These factors around positive autistic identity and feeling part of the autistic community could help to improve outcomes for these young people, although it is not clear whether these come from receiving a diagnosis or whether these can be achieved without a diagnosis.[11,14–16]

One study reported negative views of autistic young people towards their autism and the stigma they encounter, and the lack of acceptance of difference. They discussed how it is important that adults think more carefully about the messages youth receive about the diagnosis (family discussions, school / teacher attitudes, media). Efforts to normalise neurodiversity in schools / society may help positive self-understanding, and more targeted efforts to focus on individualised strengths (being detail oriented, honest, reliable) will help to build positive self-concept. At an individual level, therapeutic approaches to develop more positive and balanced perspectives on their diagnosis and their sense of self.[14]

Another study found young autistic people did identify negative aspects but these were not due to the diagnosis but around the barriers they face due to their autism.[16]

Another study concluded autistic young people who had higher autism satisfaction had better psychological well-being and lower social anxiety. Young people who felt more solidarity with other autistic people had higher psychological well-being.[15]

Many of the children in one study were aware and able to articulate their experiences, needs, and challenges, but lacked awareness and understanding regarding their diagnosis, with some unaware of their diagnosis.[17]

Diagnosis disclosure

A study looked at disclosure of an autism diagnosis by parents. Adolescents who were told they were autistic by a parent voluntarily were more likely to define autism neutrally or including strengths. The research suggested the way children are told about their diagnosis may influence their self-identity and understanding of autism.[18]

Another looked at ways diagnosis is presented by clinicians, by talking about autism as a difference rather than a deficit, can help the young person with sense making and in the development of their self-identity.[19]

A further study found young people who were aware of the diagnosis reported improved self-advocacy skills, enhanced self-awareness of personal strengths and weaknesses, and other benefits.[20]

How do young people feel about ADHD / ADD and their diagnosis?

Young people with ADHD reported feeling ‘not normal’, these narratives of being abnormal were not linked to being diagnosed ADHD, but rather to their experiences of standing out, of social exclusion and failing to connect to others. The young people had mixed feelings regarding the diagnosis, some finding it confirmed they were different, whilst others felt it helped them to better understand themselves. They linked the child’s perceptions of the ADHD label linked with whether they viewed diagnosis positively or negatively. Some ignored or adapted to having an ADHD diagnosis, others resigned to the diagnosis, letting it encompass their entire self-image. Some young people felt relief, often followed by anger at being misunderstood and often wishing they had known earlier. Some described it as helping them understand their difficulties, lifting blame from themselves over things they couldn’t control.[21]

Some studies identified stigma as an issue associated with children with an ADHD diagnosis.[22–24]

A couple of studies question the benefits of diagnosis for children with borderline ADHD behaviours.[21,25]

Personal reflections – the evidence found and not found

There was limited evidence looking at the opinions, feeling, or experiences of children and young people around neurodiversity. Most research looked at the opinions, feelings and experiences of parents or adults receiving a diagnosis.

When we consider support without diagnosis, we usually think about education and health, where support may be accessible without the need for a diagnosis, but it may be helpful to also consider other areas such as employment, police / criminal courts, social activities, transport, banking / bills / finance. In these areas concessions / adaptations are often provided to those who have a diagnosis, but I have not found any research that looks at whether this support would be provided to those without a diagnosis.

Search strategies

Embase and Cinahl

Please note for the Cinahl search the proximity operator was n3 rather than adj3

(neuroatypical or neuro-atypical or neurologic* atypical or (neurodiver* or neuro-diver* or neurologic* diver*) or (Autism* or Autistic* or ASD) or (ADHD or "attention deficit")).ab.

OR

(autism or neurodiversity or attention deficit hyperactivity disorder).sh.

AND

(diagnosis or diagnoses).ab. or diagnosis.sh.

AND

(((paediatric* patient* or pediatric* patient* or child* or young person* or young people or teenager* or adolescent* or young adult*) adj3 (view* or perspective* or opinion* or feedback or fed back or satisfaction or survey* or self-report*)) not ((parent* or parental or guardian* or carer*) adj3 (view* or perspective* or opinion* or feedback or fed back or satisfaction or survey* or self-report*))).ab.

Limit to 2018-2024

Embase and Cinahl

(neuroatypical or neuro-atypical or neurologic* atypical or (neurodiver* or neuro-diver* or neurologic* diver*) or (Autism* or Autistic* or ASD) or (ADHD or "attention deficit")).ab.

OR

(autism or neurodiversity or attention deficit hyperactivity disorder).sh.

AND

(diagnosis or diagnoses).ab. or diagnosis.sh.

AND

(identity or "perceptions" or "Diagnosis experience" or self-identification or self-identity or "self treat*" or "self diagnos*" or "self identif*").ab.

Limit to 2018-2024

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