

3rd meeting:Lived Experience

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LECTURE 4:

Support for Families of Individuals with Autism

***Dr Urmila Pillay, Chartered Clinical Psychologist, Ealing
Adult Autism Assessment Service, West London Health
Trust, London, UK***





1. sources and means of support for the family



2. support by professionals

-how to get the best out of it

-challenges



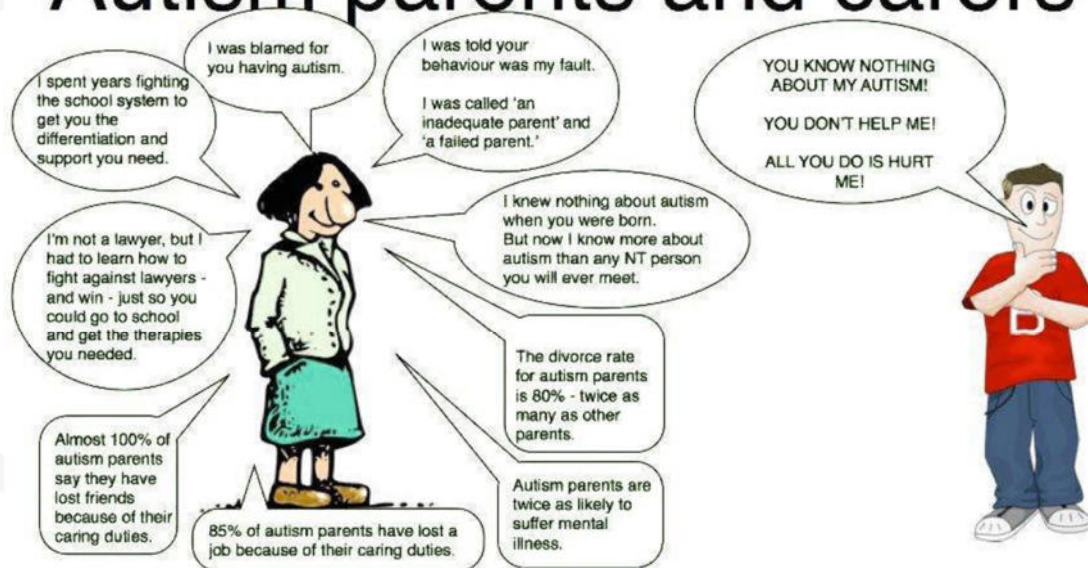
Outline

NEEDS OF PARENTS

- Pepperell, Paynter & Gilmore (2016)- Study carried out in France, 162 parents were interviewed. Six dimensions of need identified:

- Material
- Information
- Guidance
- Daily management
- Relational support
- Emotional support

Autism parents and carers



Autism parents and carers have sacrificed more, know more about autism, and do more than you can possibly imagine.

You might not think we're good enough, but I don't see anyone else helping you.

SUPPORTING PARENTS' NEEDS

- 90% of parents requested support for the following:
 - Additional **support at schools, home and improved relationships with service providers**
 - The most **important challenges-** child's communication difficulties, social interaction difficulties and daily living skills
 - Parents most concerned by- child's **lack of interaction** with others and **playing alone and difficulty in accessing services**
 - *<https://jrtd.com/manual-for-parents-of-children-with-autism-spectrum-conditions-and-professionals-in-their-circle-of-support/>*



SUPPORTING PARENTS' NEEDS

- Support programmes focused on the needs of the parents
- Emotion-focused strategies through individual therapy
- Accessing emotional and practical support (Pepperell, Paynter & Gilmore, 2016)
- Having an in-school tutor, assistance in managing child's needs or in implementing intervention and access to a source of information - contributed to increased satisfaction among parents
- Parents also expressed a need for resources to assist them in their role in providing sexual education for children with Autism (Mackin et al. 2016)



HAND
Hertfordshire Additional Needs Database

Are you a parent or carer of a child or young person with an additional need or disability aged 0 - 25 years?
e.g. Multiple and complex health needs
Autistic spectrum disorder, ADHD, communication disorder
Visual or hearing impairment
Learning disability
Chronic physical illness
Significant pre-school delay
Physical disability

What HAND can do for you:

- A newsletter each term - www.hertsdirect.org/handnews
- Concessions on leisure facilities
- Information on benefits, activities, support groups and much more
- An opportunity to influence planning of future services

You can join HAND online at www.hertsdirect.org/hand or call 01992 556984 or email hand@hertfordshire.gov.uk for a paper copy of the membership form and more information

Don't miss out

Children's Services
www.hertsdirect.org/hand
0300 123 4043



<https://www.hct.nhs.uk/your-health/managing-conditions/asd-diagnosis-service/autism-information-and-support/information-and-support-for-parents/useful-resources-for-parents-of-children-with-autism/>

IMPORTANCE OF SOCIAL SUPPORT



- Social Support ‘is an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well being of the recipient’ (Shumaker and Bournell, 1984, p.11)
- Critical for the well-being of care givers as it helps in managing stress
- The more challenging the need of the child / adult with autism, the more likely the family will seek support.
- Boyd (2002)- The greater the mothers were under stress, the more likely they were to seek support
- Informal network (friends and family) was more effective to buffer stress

BENEFITS OF SOCIAL SUPPORT

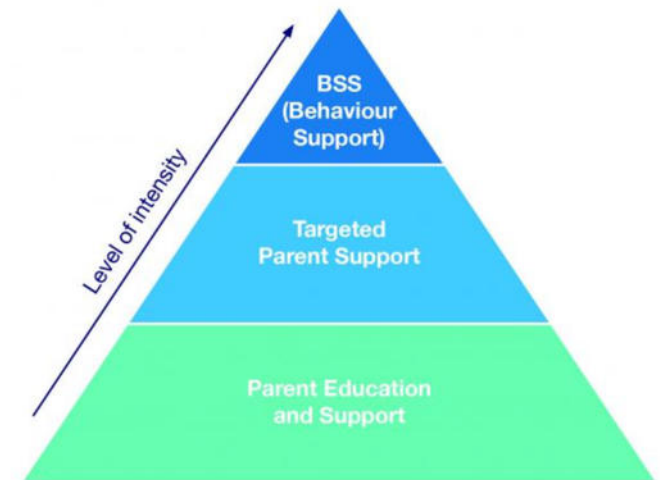
- Boyd (2002) - Parents who received social support related emotionally better to children with autism as they were less likely to experience depression and anxiety.
- Parents who did not receive support were more likely to experience depression and anxiety.
- Studies on mothers who have children with Autism showed that family support was associated with greater optimism and higher well-being (Ekas, Lickenbrock & Whitman, 2010)
- Partner and family support had a direct impact on the well-being of the mother. The more the support from the partner and the family, the better was the well-being of the mother (Ekas, Lickenbrock & Whitman, 2010).

Social support



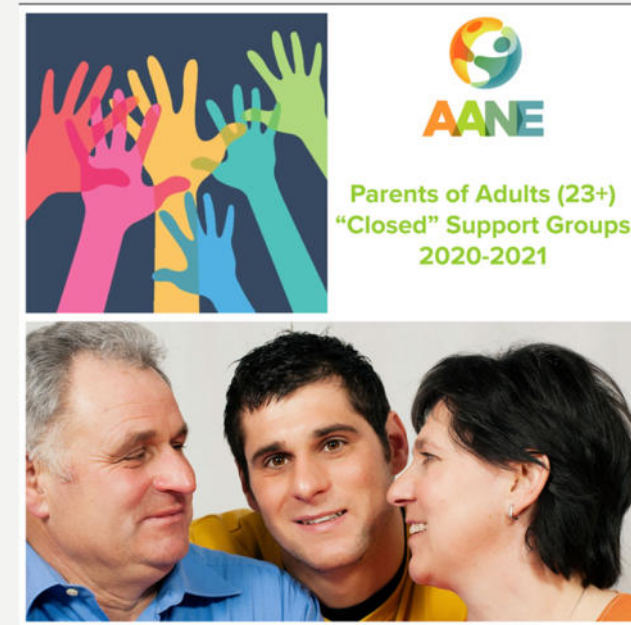
SUPPORT DURING EDUCATION

- More challenges in university- children stay at home till then
- parents were their greatest resource because they know their child best and can offer valuable insights. Barnhill (2016)
- Parents are viewed as partners in the student's program.
- Adult child are encouraged to learn self-advocacy skills and that it is the student's responsibility to contact the parents.



SUPPORT DURING EDUCATION

- Needs of parents and child who has Autism differ.
- Parents often consider their child's skill deficits the most salient factor in planning for postsecondary education (such as availability of social support and mentoring) and hence requested social interaction training and independent living training.
- while youth with ASD may place greater value on environmental concerns such as coursework and campus disability awareness (Camarena & Sarigiani, 2009).



SUPPORT FOR PARENTS/CAREGIVERS/SIBLINGS

- Families may need additional support in the house (home support services), time for themselves as a couple or as a family (respite services), information in managing their child's needs (parenting training) and they may need support from other parents in terms of sharing similar experiences and supporting each other (support groups).
- The diagnostic process of ASD is difficult and stressful for parents and the lack of information often creates additional stress for parents/caregivers. The need for information is frequently reported by families rather than other needs (Bailey and Powell, 2005).
- parenting programs, such as the **Hanen Parent Programmes More Than Words** (Sussman, 1999) and **The Incredible Years** (Sutton et al. 2004), should be accessible for all parents who need support. Training programs for parents of children with autism spectrum disorders demonstrate positive effects for both parent and child outcomes in terms of increasing parent skills and child language and communication outcome (Patterson et al., 2012).

SUPPORT FOR PARENTS/CAREGIVERS/SIBLINGS

- **Support groups** - Several studies have demonstrated the positive impact of parent support between families of children with ASD, in the context of support groups (Mandell and Salzer, 2007; Luther et al., 2005).
- Parents of children with ASD could benefit from this 'informal' support in group in order to improve their understanding of their child's needs and difficulties. Parents would also know where to seek support if needed. Sharing information is another aspect that support groups might find beneficial. It is not easy for parents to discuss their difficulties in front of a group.
- **Psychotherapy/Family therapy** Psychotherapy (family therapy) is often recommended for children with ASD and their families (e.g. Ramisch, 2012).
- home-based and clinic-based family therapy offers support to families with children on the autism spectrum disorder which help them achieve strategies for managing family stress factors.

PROFESSIONAL SUPPORT

Psychiatrist- helps manage mental health through medication. There is high incidence of depression and anxiety in individuals with autism hence it is important that their mental health is reviewed by a Psychiatrist and appropriate intervention given.

Clinical Psychologist- provides therapeutic help to people with Autism and their families so as to cope better and improve their quality of life. Their interventions include but not limited to:

Social skills training- individuals with Autism have difficulty communicating with others and understanding others and hence giving social skills training can help them improve their skills so they are able to function better in the society

Mindfulness- to help with depression and anxiety in both individuals with ASD and family members

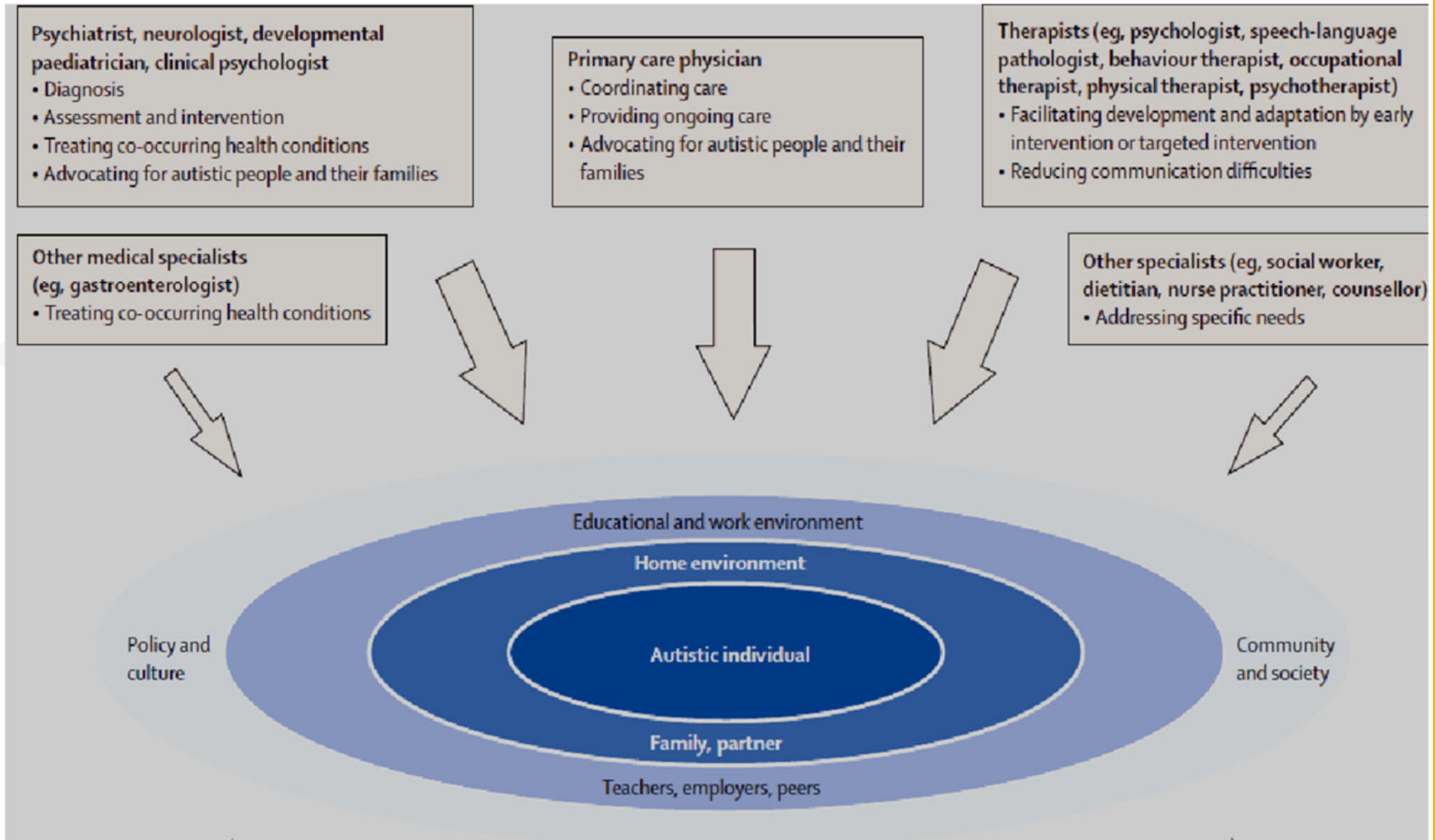
Family therapy- to help family understand the difficulties of Individuals with autism and how they could help and support them as well as to how to improve their functioning as a unit .

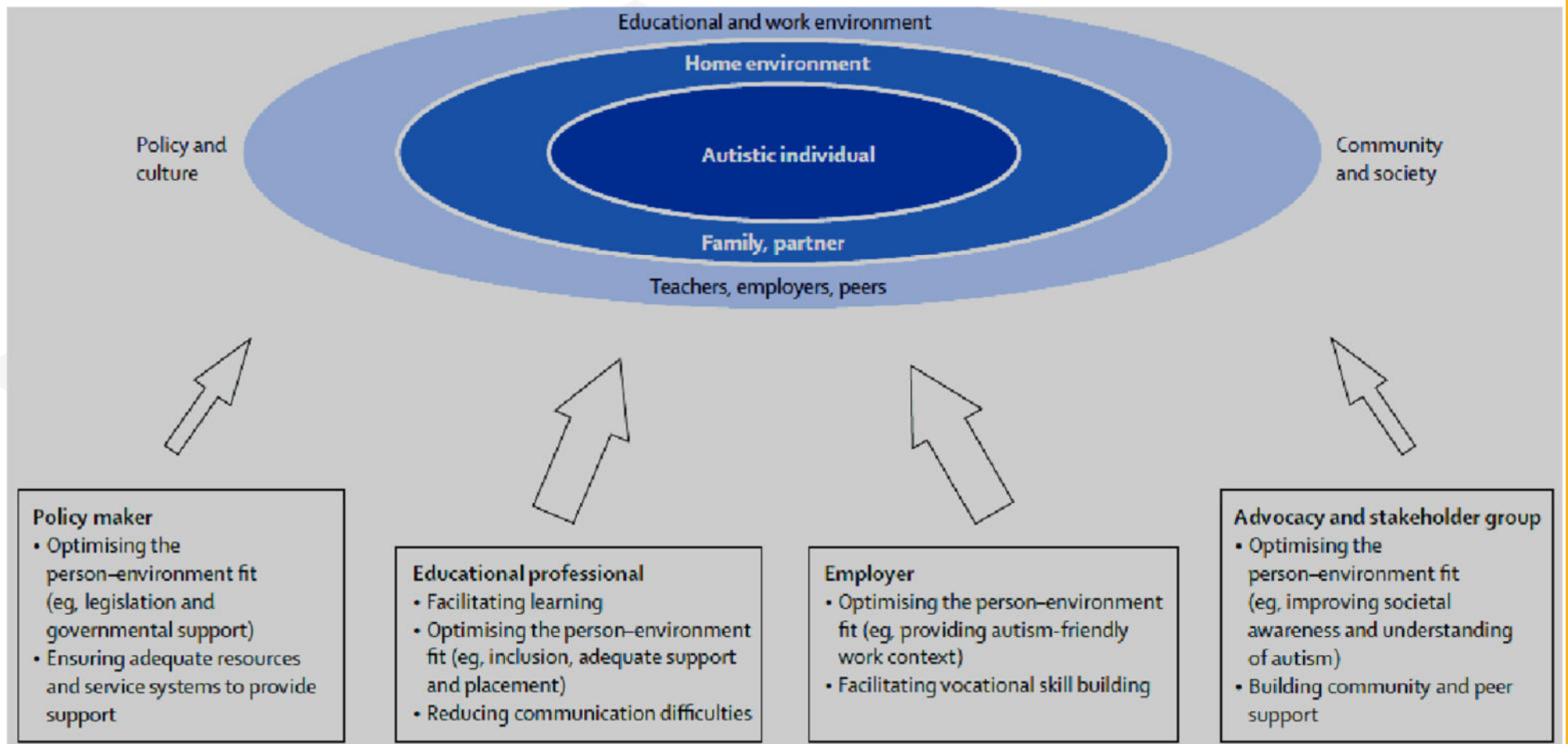
Support for care givers- Care givers go through a lot of stress, anxieties , worries, depression etc. Hence it is important that they are supported by a professional

PROFESSIONAL SUPPORT

- **Occupational Therapist:** important role in helping individuals with autism lead a better life. Sensory integration therapy is carried out by OTs, with the focus to help them deal with their hypo sensitivities and hyper sensitivity so their quality of life improves and they function better.
- e.g. of Hyposensitivity-Needs to keep touching certain kind of cloth.
- e.g. of Hypersensitivity- not able to tolerate certain kind of noises.







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THANK YOU!

