

Performance and Social Life Perceived by Young Persons With ADHD and Autism: A Chat-Log Analysis*

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This study focuses on young persons with ADHD (attention-deficit/hyperactivity disorder) and ASD (autism spectrum disorders), and on their everyday life. Follow-up studies on ADHD and ASD persisting into adulthood describe residual impairments affecting everyday life. Previous studies have focused on interventions and programmes aiming to support these young persons in their attempts to learn, understand and manage social interaction in real life. However, few studies involve the young person's reflections on their own view of their everyday life. The aim was to elucidate how young persons with ADHD and ASD describe aspects of everyday life based on analysis of Internet-based chat logs. Twelve young persons (seven males and five females aged 15-26 years) with ADHD and ASD participated in an eight-week IBSC (internet-based support and coaching) study, comprising chat via Internet. Data consisted of 12 chat logs (445 pages of text) produced interactively by the participants and their personal coaches. The text was analysed using qualitative content analysis. Two themes were revealed: (1) "When performance is an achievement" with the subthemes; "to cope with the problems caused by the disability", "the impact of treatment on performance", and "to perform well enough"; and (2) "When social life is an achievement" with the subthemes; "desire for closeness" and "dealing with social relations". The study reveals the young persons' efforts to overcome obstacles to performance and social interaction stemming from their disabilities. They master strategies in terms of SOC while simultaneously they actuate their laborious transition into adulthood. Their ability to express these processes in an IBSC chat became evident. Using e-coaching in this population makes available new opportunities for health-care professionals to pay serious attention to these young persons' problems.

Keywords: ADHD (attention-deficit/hyperactivity disorder), autism, qualitative content analysis, effects of medication, everyday life, Internet-based support, social interaction, young persons

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Introduction

The focus of this study is on young persons with ADHD (attention-deficit/hyperactivity disorder) and ASD (autism spectrum disorders) and their everyday life. Recently, research has shown that some of these conditions, ADHD in particular, which have previously been considered as childhood conditions, persist into adulthood. Follow-up studies of ADHD (Faraone & Biederman, 2005; Kessler et al., 2006; Rasmussen & Gillberg, 2000) and ASD (Billstedt, I. C. Gillberg, & C. Gillberg, 2005; Cederlund, Hagberg, Billstedt, I. C. Gillberg, & C. Gillberg, 2008) describe these disorders in adults, with persisting symptoms, affecting daily life. One study estimates the prevalence of adult ADHD as 4.4% (Kessler et al., 2006). The prevalence of ASD varies from three per 10,000 regarding Asperger syndrome to 13 persons per 10,000 regarding autism (Fombonne, 2005). However, a study from a Swedish region found that 20.5 per 10,000 screened positive for ASD (Gillberg, Cederlund, Lamberg, & Zeilon, 2006).

A literature review by Primich (2012) showed the importance of regarding the adult person with ADHD within a life context, as symptoms and impairments of ADHD impacted daily living and are more difficult to map for adults than for children. A follow-up study on important life activities in 149 young adults with hyperactivity aged between 19 and 25 years (Barkley, Fischer, Smallish, & Fletcher, 2006) shows that they had fewer years at school, and had lower grades in their degrees compared to an age-matched community control group. More of the young adults with hyperactivity were employed rather than studying, and more often also had full-time jobs. More of them had lost jobs compared to the community control group. The two groups did not differ concerning the extent of social relations. However, those with hyperactivity reported having fewer close friends, more sexual partners and had more often become parents. They had more loans and less savings and fewer had ever had a credit card (Barkley et al., 2006). Young persons' perceptions about their own ADHD and their medication were investigated by means of interviews with 15 adolescents aged between 14 and 17 years attending high school (Knipp, 2006). The adolescents described their initial doubts about medication, which became changed positive as improvements in school and family relations appeared over time.

In one study mothers reported on their adolescents and adults with autism, regarding the individuals' relations with friends and the kind of social and leisure activities they participated in (Orsmond, Wyngaarden, & Seltzer, 2004). The researchers revealed that nearly half the sample, consisting of 235 persons, had no relationships with friends except for those in pre-organized groups and activities. Further, it was challenging to establish new relations as well as maintain friendships. The most common activity performed by three quarters of the participants was some kind of physical training including taking walks.

Turner Brown, Perry, Dichter, Bodfish, and Penn (2008) evaluated a group intervention for improving social cognitive function in high-functioning persons with ASD. The pilot study included six participants in the intervention group and a five-person comparison group receiving the usual treatment. The intervention included "emotion training", "figuring out situations", and "integration" adapted specifically for ASD. The intervention showed good feasibility. Even though the number of participants was low, there were some promising results in the intervention group, where social skills improved in contrast to the participants who received the normal treatment. In a study by Ratto, Turner-Brown, Rupp, Mesibov, and Penn (2011), social skills were measured in 20 high-functioning young persons with ASD aged between 16 and 22 years, and in a healthy control group consisting of 20 young persons. A role-play focusing on the ability to change behavior in social life according to the situation was used to assess social interaction. The young persons with ASD showed

few significant changes regarding the effects of interaction whereas the control group showed significant changes across different social situations. A 12-month leisure program and its influences on stress and quality of life were studied in 37 individuals with ASD aged 17 to 39 years, and an age-matched control group from a waiting list, consisting of people with ASD (Garcia-Villamisar & Dattilo, 2010). The program aimed to facilitate interaction and participation in spare-time social events. Quality of life increased significantly on the items satisfaction, independence, competence, and social interaction for the ASD group and their levels of stress decreased significantly. The control group did not show significant changes in either quality of life or stress.

Previous studies have focused on how to develop social competence through such group interventions as role-play and leisure programmes aimed at supporting the young persons with ADHD and ASD in their efforts to learn, understand, and manage social interaction in everyday life. The interventions studied were mainly tested and evaluated in quantitative studies. Few qualitative studies have been performed in this area and few studies have been conducted to develop individual methods for supporting young persons with ADHD and ASD. Even fewer studies concern the young persons' reflections on their own views of their everyday life. Consequently, this area requires further explorations.

Aim

The aim of the study was to elucidate how young persons with ADHD and ASD describe aspects of everyday life based on analysis of Internet-based chat logs.

Method

Design

This is a qualitatively designed study emanating from a larger intervention project, "NP Young Coaching". The intervention project explores whether a model of structured IBSC (Internet-based support and coaching) improves quality of life and mental health in adolescents and young adults with NPD (neuropsychiatric disorders). The intervention took place in a region in the south of Sweden between 2008 and 2010. In the present paper, adolescents and young adults aged 15-26 years are called "young persons".

IBSC

The second author developed the model for IBSC, which was intended as a home-based interactive intervention. For this purpose, a computer program for young persons with NPD "Salut Chat" was developed in cooperation with Net Union, Switzerland. The model comprised eight weeks of IBSC; the young person was offered twice weekly chat sessions with his/her personal coach over the Internet. Three face-to-face meetings were offered with the coaches; one meeting before the chat period, and two meetings during the eight-week IBSC period. All sessions were pre-booked and scheduled to last between 30 and 60 minutes. The coaches were all females; three psychologists and one educational therapist. All had special competence to encountering young persons with NPD. When the young persons chatted with the coaches, they were usually at home and the chat session took place at times they found convenient. Both the young persons and the coaches had access to the chat program via the Internet. The participants joined the intervention because they wanted help with such personal problems as, for example, how to cope with studies, how to deal with being assigned a neuropsychiatric diagnosis and how to seek employment (Wentz, Nydén, & Krevers, 2012).

Participants

The inclusion criteria were: aged between 15 and 26 years; having a diagnosis of ADHD, and/or ASD diagnosed according to DSM-IV (the Diagnostic and Statistical Manual of Mental Disorders, 4th edition) (APA, 1994); with access to a computer with an Internet connection at home. Exclusion criteria were: having a current psychosis, alcohol or substance abuse, major depression (only if it was considered too severe), severe dyslexia, intellectual disability and/or currently involved in criminality.

Twelve young persons: seven males and five females (median 17 years, mean age 19.6 years), were included consecutively. Ten participants had ADHD, and seven also had another NPD, in six of these cases it was ASD. Eight participants were students: two at elementary school, five at upper secondary school, and one at university. Four participants were unemployed.

Data Collection

Data were collected after the completion of the IBSC and consisted of the 12 chat logs produced interactively between participants and coaches during the intervention. The text comprised 445 pages in total. The chat logs were rendered anonymous.

Analysis

A content analysis (Krippendorff, 2004), accomplished stepwise in order to describe patterns and themes (Patton, 2002), was deemed appropriate for descriptive analysis of this large amount of text. In content analysis, the text is divided into meaning units, which are then labeled with codes describing the individual content. Thereafter, the codes are sorted into subthemes and interpreted into themes (Krippendorff, 2004).

Reading all the text from the chat logs, as the starting point for the analysis, provided an overview of the data. Simultaneously, the text was divided into meaning units, parts of the text that shared the same content. This analytical process led to preliminary themes and guided the coding process which was subsequently carried out in NVivo9. The codes, which were compared regarding differences and similarities, were then sorted into subthemes and interpreted into the final themes. The body of text data was so large that it was divided and the study is, therefore, presented in two articles (Hedman Ahlström, & Wentz, 2014). In the present paper, themes focusing on performance and social life were grouped together to form results. The results emerged from analysis of all chat logs and no participants were excluded.

Ethical Considerations

The Regional Ethical Review Board in Gothenburg (GU 013-08), approved the study, and the ethical reflections and judgements were consistent with the World Medical Association Declaration of Helsinki (2008).

Results

The results comprised two themes: (1) “When performance is an achievement” with the subthemes; “to cope with the problems caused by the disability”, “the impact of treatment on performance”, and “to perform well enough”; and (2) “When social life is an achievement” with the subthemes; “desire for closeness” and “dealing with social relations”.

When Performance Is an Achievement

To cope with the problems caused by the disability. The young persons described that they understood they had problems and wanted change in terms of being unburdened of the troubles caused by the disability.

Becoming aware of the disability could have happened coincidental with the young persons unprepared to receive this information. Other peoples' opinions about their problems also came as a surprise.

Ebbe: "Yes, I have recently been reminded that I still have shortcomings that need to be dealt with, but I see it as something positive because I do not get discouraged and give up because of that knowledge".

Being given this new information about oneself regarding, for instance, having difficulties in conversational situations because of the inability to manage the rules of taking turns, gave rise to feelings of sorrow and resignation. However, some of the young persons talked openly to friends about their disability, which brought them understanding and support. This was visualized in the following chat dialogue:

Coach: "How often do you talk to your friends about your diagnosis?"

Alice: "Quite often. They think I am a real fighter when it comes to my diagnosis. They have got a deeper understanding that I cannot cope etc. They tell me that they have almost the same problems and wonder if perhaps they also have the same diagnosis".

Understanding a personal mistake was described, for example, as the ability to realize when they had crossed the border of decency in interactions with other people, and the necessity to apologize for that. Failure to behave in an acceptable way concerned social interactions which led to misunderstandings due to the young persons' uncertainty about social codes. This could happen at work causing low self-esteem and a sense of confusion. It could also happen in sexually charged situations causing anxiety. The young persons told they knew they sometimes talked too much to the wrong people in the wrong situations and about the wrong topics.

Possessing self-awareness was described as having considered personal restraints and talents, as well as their consequences. This included the young persons reflecting on misjudgements, such as on how they prioritized time; too often spending too long playing various kinds of games (e.g., computer games) which intruded negatively into their everyday lives. They became aware of this when they described symptoms of abstinence.

Their capacity to persevere "...I could go on forever..." was regarded as a talent which could be undermined by feelings of depression. The resulting reduced capacity was regarded as a problem which was difficult to put up with. Awareness of the consequences of depression on everyday life was reflected upon. One way of being contraproductive was to think negatively about their own capacity and about important people. This was part of an overall negative attitude towards oneself.

David: "And then another reason I think has to do with me often thinking very negatively, because it is easier to have low demands and not anticipate disappointment. I must also try to change that".

Failure to understand oneself was described by the young persons as having no idea why they thought, felt and acted in the way they did. It involved their attention and concentration, physical sensations, and their inner emotional life. Sometimes, difficulties understanding their own actions precluded the young persons from finding solutions to pragmatic problems, for example, managing to set off for school in time.

The impact of treatment on performance. Some of the young persons described positive experiences of starting medication with psychostimulants. Even on low doses of medication they noticed changes in their ability to concentrate, which led to expectations of further improvements to come. One noticeable positive consequence of taking the medication was described as being able to control their temper through their curbing impulsivity, which was otherwise difficult to do. The young persons also described improvements in

self-confidence as an effect of the medication. They also described feeling calmer than before after a busy day.

Alice: "... you feel more confident like, and you become more mature actually hahah :)"

Alice: "I've got such amazingly good self-confidence. I dare to question and talk more. I'm not afraid of making mistakes, and the best part is that I don't feel stressed and nervous anymore, as I did before. There is so much I'm happy about and I cannot choose one because there are several things :)"

Being able to improve their performance in exams was an unexpected and gratifying experience. Earlier feelings of inability due to not being able to understand the tasks in school changed into a growing sense of self-reliance. Fatigue decreased and social life became better.

Some of the young persons experienced the medication negatively when it intruded excessively on personal characteristics that they valued. In this context, personal "creative chaos" was described as important as is shown in the following chat conversation:

Ebbe: "Creative chaos is messy and confusing, but for someone who is in it, it looks quite logical. For example, an untidy desk, no one except the owner (of the mess) can find anything in it, but that person would not find anything if it were tidied up by someone else".

Coach: "It's a bit difficult to understand that the chaos can be creative, but I understand that it may be easier to recognize oneself in it".

Ebbe: "But then you come to the question of how to define creativity, and it is not possible. I need the mess, it is a part of me and the dose of the medicine I took cleaned me up so that I could not function creatively".

Medication undermined the ability to reflect on ideas. The reflection process was launched by verbalizing a thought through expressing it loud, which, in turn, was prompted by an impulse. This resulted in a chain of thoughts and reflections which accelerated and were regarded as the creativity itself. When on medication, the escalation of thoughts never occurred which was regarded as an undesirable loss, engendering negative attitudes towards the medication.

The unfamiliarity of taking medication on a regular basis led the young persons to make unfortunate mistakes, for example, they forgot that they had already taken the daily dose and took another. Negative side effects could also appear, such as difficulties in relaxing and sleeping. Furthermore, forgetting to take a dose for some days and then starting to take the medication again could lead to problems with concentration and strange bodily sensations. The consequent experiences of lack of control over their thoughts were unpleasant. The side effects of medication sometimes led to interruption of the medication. Then the young person felt, almost immediately, that they performed better at school and were happy to be themselves again.

To perform well enough. Being able to carry through tasks was described as having longer or shorter periods of concentration when it was possible to get a lot of work done effectively. Some of the young persons said that they had received positive feedback from their employers, who were satisfied with their efforts at work. To participate in activities and accomplish tasks on a voluntary basis, even though in such an organized form as "daily activities", was satisfying. Alternating tasks to sustain interest in what they had to do was important, allowing them to enjoy the work and complete the tasks.

The young persons described ways of coping with homework at different educational levels; following guidelines from teachers helped. It was also important to really concentrate and read the tasks properly, but keeping themselves within the recommended framework was problematic:

Håkan: "I think it is just following the template and starting from the instructions the teachers had given me. However, I usually like to be innovative which leads to me floating among the clouds in the end".

Using the special time set aside at school for their own work helped some of the young persons to be efficient and eased the burden of doing school work at home. Spending time on homework paid off instantly in higher scores. Meticulous planning and starting their homework early were sometimes needed to keep in step with the curriculum and to minimize anxiety. However, not being at all worried about performing sufficiently well at school was also described. The young persons were aware that they needed knowledge to manage life and wanted to learn about complex phenomena in life. The knowledge they needed ranged from what impact the advanced mechanisms of the brain have on their own disability, to how to learn to be empathetic.

When Social Life Is an Achievement

Desire for closeness. The desire for closeness concerned both romantic relationships and relationships with friends and was characterized by ambivalence. To be in love was described as a wonderful feeling and that both sexes may be the object of their feelings.

Frida: "I am often in love. I really want a boyfriend. But I am unhappy with myself so I cannot believe that someone would think I am attractive".

Having a relationship was complicated because of the young persons' difficulties in communicating about their own disability, and because of the other person's emotional reactions.

Ebbe: "She has just met the happy, spontaneous and extrovert me. This weekend she saw me at my lowest and I think she may have had other thoughts since then".

Ebbe: "As I have noticed a clear difference in her way of talking and being with me ever since".

The young persons questioned whether they had the self-esteem and self-confidence to have relationships, as shown in the following quotation, characterized by self-knowledge:

Frida: "I would like to talk to you about one thing that pops up in my head now and then. I will turn 18 soon, but I have no boyfriend and I have never even kissed anyone. I have never partied, am rarely at home with friends. I do not drink alcohol, but when I am with any of my older friends then I drink cider or water when they drink alcohol. I hate to go shopping... Would you classify me as an abnormal teenager?"

Relations with friends were described in terms of long-term friendships characterized by having similar interests and an openness between them. Friendship could, however, be difficult to handle when one did not know how the friend valued the friendship when they no longer shared interests and they had less contact with each other. Some of the young persons said they needed friends with varying characters to help them develop personal characteristics, feelings, and maturity. They also said they knew about sexuality but wanted to learn a lot more about sex, relationships, and adult life.

Dealing with social relations. New contexts, new situations, meeting new people, and not knowing what to do or how to behave sapped on self-confidence. The young persons said that they could not explain their own opinions clearly to others. This shortcoming delayed the chance to accomplish anything important. It was also a problem to show a positive attitude towards others by being polite and understanding but in fact not agreeing with what was said or decided. Some young persons stated that they always told the truth by being straight about personal and intimate circumstances. They considered this behavior both natural and uncomplicated. They also described how when obsessions appeared, they were impossible to stop, and affected social relationships; they grew too big to resist and finally had to be expressed to others. Afterwards, this resulted in many hours of anxiety.

The young persons described feeling unsure of themselves. They always felt uncertain in everyday life and thought they behaved strangely. Some of the young persons sometimes took on the role of an actor, and used the most suitable role for the moment. Being the “clown” was one way of handling social interactions. The young persons worried about hurting people as they felt they did not know how to interact properly, and described a desire to feel calm and secure. The following quotation illustrates such situations:

Håkan: “When I am with the girl I am seeing now. When I rehearse. When I am with a small group of close friends. When I am with a person who wants help to sort out something he or she has become entangled in”.

Being able to interpret the other person’s mood and being a good listener helped some of the young persons in their social interactions. However, the opposite was also described:

Håkan: “... When I am actually at work, I find it difficult to socialize and pick up the atmosphere”.

Being unable to handle the situation could be problematic when situations seemed to be unjust and illogical, and everything became incomprehensible. Confidence in other people then declined. Being quiet as opposed to answering in a loud voice and using hard words was way of trying to avoid trouble at home. The verbal outbreaks of parents and siblings were described as situations that were difficult to handle. However, some young persons described uncomplicated contact with family members and friendly relationships with classmates.

Discussion

The findings show that the everyday life of young persons with ADHD and ASD is marked by overcoming hindrances to performance and social interaction. Hence performance and social life become an achievement in themselves.

The first theme, “when performance is an achievement”, reflected the young persons’ understanding of the problems caused by the ADHD and ASD per se, and the consequences these problems have on everyday life. The young persons’ insight into the meaning of ADHD and ASD was made visible when they expressed their feelings and thoughts in the chat. Self-awareness revealed an ability to reflect on strengths and weaknesses. On the other hand, failure to understand oneself revealed the lack of insight necessary for managing everyday life. This lack could be a fundamental topic for reflection and support. Comprehensibility, manageability, and meaningfulness have been described and developed by Antonovsky (1987) as the foundation of SOC (a sense of coherence). In the IBSC pilot study (Wentz, Nydén, & Krevers, 2012), SOC had improved significantly in the young persons with ADHD and ASD at the six-month follow-up. SOC is considered to promote health and protect against stress. Edbom, Malmberg, Lichtenstein, Granlund, and Larsson (2010) show that SOC correlated with symptoms of ADHD in the transition into young adulthood. Adolescents at 16 years of age who described better SOC showed fewer ADHD symptoms at the age of 21 years. The authors conclude higher SOC scores act as a protective factor in the long-term outcome of ADHD.

Some young persons in our study described the possibilities and limitations connected with pharmacological treatment. The therapy affected everyday life in terms of improvements in their capacity at school (compare with Knipp, 2006) but the negative side of taking psychostimulants also became visible in descriptions of effects on personality and a weakening of important talents, leading to interruption of the medication. Brinkman et al. (2012) describe young persons with ADHD experimenting with being on and off medication, resulting in an improved insight into the relations between medication and everyday life with

ADHD. This undisciplined and selective use of medication was not evident in our study but rather a random variation in dosage caused by forgetfulness and unfamiliarity with taking medication. Adherence to prescriptions of medication is obviously an important topic for healthcare professional to support, as is the subject of managing medication independently (compare with Wolf et al., 2009).

In our study, ways of performing well enough revealed the young persons' efforts to do their utmost on their own level based on their own capacity. Some of them felt satisfied with their efforts. However, Barkley et al. (2006) reveal a life situation for young hyperactive persons characterized by drop-out from school and early entry into work life and parenthood. Cederlund et al. (2008) also describe the life situation of persons with ASD, with a very low level of education and lack of work, hobbies, and friends. According to Antonovsky (1987), meaningfulness is related to motivation and emphasizes what is important in life. It could therefore be beneficial to offer the young persons with ADHD and ASD the opportunity, to reflect on meaningfulness; it may even be necessary when they have negative thoughts about their own capacity in everyday life situations. In our study, the young persons described the ways in which they found strategies for coping with school and work. For instance, in order to concentrate, they used strategies to control both their thoughts and actions in order to prevent being engulfed by anxiety and stress. This could be seen as manageability (Antonovsky, 1987) and indicates the young persons' processes for developing SOC, which, naturally, should be encouraged.

In the second theme, "when social life is an achievement", the desire of the young persons with ADHD and ASD for closeness became evident; a desire like that of young persons in general. Arnett (2000; 2001) describes how transition into adulthood nowadays can be considered as a prolonged period of independence in order to explore and develop identity. In addition to the areas of work and world views, love plays an important part in exploring identity (Arnett, 2000; 2001). In our study, the young persons questioned their self-esteem and self-confidence. A negative self-image may lead to failures in exploring love, sexuality, and romantic relations. The openness the young persons revealed regarding these topics indicates that they are important themes even for an IBSC model to address. In the present study, the longing for a close friendship was described, and the need for several friends was emphasized. However, young persons with ADHD and ASD normally have only a few or no close friends (Barkley et al., 2006; Orsmond et al., 2004). This can be perceived as a stressful situation indicating feelings of being excluded from social interaction, which can be difficult to understand for a young person. This topic could be addressed by healthcare professionals working with comprehensibility in relation to SOC (Antonovsky, 1987). It seems that the young persons in our study were aware of both a self-imposed pressure and expectations from other people leading to them taking on a subordinate role in social life. This behavior has a negative impact on the young persons' self-image and from a longer perspective results in social isolation. Studies of interventions targeting social skills (Garcia-Villamizar & Dattilo, 2010; Ratto et al., 2011; Turner Brown et al., 2008) show that persons with ASD can improve their social competence. Enabling the young person to understand social interaction, and manage social situations should be important issues for IBSC, as the model offers an opportunity to consider both manageability and meaningfulness (Antonovsky, 1987). The guidance of a coach or a healthcare professional would allow the young person to reconsider what social relations they should invest emotion and energy in.

One limitation of the present study is the small sample consisting of only 12 persons, not all of whom completed the IBSC leading to a smaller amount of available data. Further, only a part of the total analysed chat log text was representing the outcomes for this study. Nevertheless, the study reveals the young persons' efforts to express their thoughts as they discuss everyday life, in the chat with the coaches. Content analysis

(Krippendorff, 2004) was suitable for application to the data from the chat logs. To ensure credibility (Leininger, 1994), each stage of the analysis was discussed in detail by the two authors, and two different perspectives enriched the analysis process with depth and breadth. Transferring relevant aspects of the findings (Leininger, 1994; Patton, 2002) from this study to other young persons with ADHD and ASD could bring about a deeper understanding of their everyday life, hopefully making their situation more visible.

Conclusion

Our study shows the young persons' efforts to overcome obstacles to performance and social interaction. They master strategies in terms of SOC while simultaneously they actuate their laborious transition into adulthood. Their ability to express these processes in the present IBSC project became evident. The implications of the findings are that new opportunities are available to healthcare professionals to pay serious attention to these young persons' problems. Using e-coaching in this population could facilitate contact between the young persons with ADHD and ASD and the medical and healthcare services.

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