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PERCEPTIONS OF BENEFITS OF OCCUPATIONAL THERAPY
FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS

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This dissertation was submitted in part fulfilment of requirements
for the degree of MSc Autism

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ABSTRACT

Autism Spectrum Disorders (ASD) are Pervasive Development Disorders (PDD) causing qualitative and quantitative impairments in the areas of communication and social interaction, as well as repetitive and stereotyped activities, interests and behaviour (American Psychiatric Association, 2000). Many individuals with ASD are addressed to occupational therapy services, although there is little research into the usefulness of occupational therapy intervention for this group of clients. Therefore, this study aimed to determine whether service users and providers perceived occupational therapy as beneficial for people with autism, and why. In this purpose, individuals with ASD, family members, and occupational therapists from both France and the UK were invited to take part in an online survey about their experience and their opinion of occupational therapy services. The results showed that most respondents perceived occupational therapy as beneficial for people with ASD, and that they were satisfied with the intervention. Indeed, they observed progresses in diverse areas, such as the autonomy in activities of daily living, motor skills, communication, social interaction, behaviour, executive functions, quality of life, and sensory processing. However, many improvements still need to be done, including a better understanding of autism, more specific assessments and interventions, more information about this profession and how it can help, and a better accessibility of these services for individuals with ASD. This study had a small sample size, and the evidence on the efficiency of occupational therapy for persons with ASD still remains weak. Further research into this topic is therefore required.

CHAPTER 1: INTRODUCTION

Autism Spectrum Disorders (ASD) are Pervasive Development Disorders (PDD) causing qualitative and quantitative impairments in the areas of communication and social interaction, as well as repetitive and stereotyped activities, interests and behaviours (American Psychiatric Association, 2000). Occupational therapy is a health profession that helps people maintain, gain or recover a maximal autonomy in their daily life. Many individuals with ASD, especially children, are addressed to occupational therapy services, although there is a lack of evidence regarding the usefulness of this treatment for this group of clients: 6903 children were seeing an occupational therapist in Scotland in February 2002 (Scottish Executive, 2003), and children with ASD represent 19% of the patients of occupational therapists working in paediatrics in the United Kingdom (Howard, 2002). Thus, the number of children with ASD who were seeing an occupational therapist in February 2002 might be approximately 1312, which would represent 23 percent of the children with ASD living in Scotland, as the estimated number of children with ASD living in Scotland is 5600 (Public Health Institute of Scotland, 2001). The SIGN98 (Scottish Intercollegiate Guidelines Network, 2007) and the PHIS Report (Public Health Institute of Scotland, 2001) concluded that individuals with ASD should have access to occupational therapy assessments and interventions, although there was insufficient data to make any official recommendation: *“The available studies were insufficient to support an evidence based recommendation about occupational therapy for ASD, including the use of particular interventions such as sensory integration. [...] Children and young people affected by ASD may benefit from occupational therapy for generic indications, such as providing advice and support in adapting environments, activities and routines in daily life.”* (Scottish Intercollegiate Guidelines Network, 2007). Indeed, some studies have shown the benefits of occupational therapy for individuals with autism, but they are not numerous, and most of them are focused on sensory processing based interventions only. This lack of research could be due to the fact that it is perhaps relatively uncommon for occupational therapists to work with individuals with ASD (Howard, 2002), or to the fact that occupational is a relatively recent field compared to

psychology or medicine, which have a long history of research (Schaaf & Miller, 2012). It seems therefore crucial to investigate the outcomes and the possible benefits of the different types of occupational therapy interventions used with individuals in the spectrum, and to determine whether and how these services need to be improved.

It seems difficult to conduct an experimental study into the outcomes of occupational therapy because of the individual nature of the work. Indeed, occupational therapists usually work with individuals on a one-to-one basis, and rarely with large groups (Watling, Deitz, Kanny & McLaughlin, 1999). Moreover, the autism spectrum covers a large variety of individuals who experience different difficulties and have different needs. It is therefore complicated to empirically measure the outcomes of an intervention provided to individuals with ASD. Thus, research into evidence-based practice tends to rely increasingly on case studies and assessment of the social validity, which can be defined as the satisfaction of service consumers and providers with the goals, procedures, and outcomes of the interventions. Therefore, this study explored the adults with ASD, family members, and occupational therapists' perceptions of the benefits of occupational therapy services. Do they perceive occupational therapy as beneficial for individuals with ASD? And why do they think it is (or not) beneficial? In order to answer these questions a questionnaire was addressed to occupational therapists, parents or other relatives of individuals with ASD, and adults with ASD. The research was conducted both in France and in the UK because it allowed to double the number of participants. Moreover, as the researcher is a French occupational therapist currently living in Scotland, it was easy for her to translate the materials into French. This survey should allow to estimate service users' and providers' satisfaction with occupational therapy practices, whether occupational therapy seem to meet the needs of people on the spectrum, and to suggest some possible improvements.

CHAPTER 2: LITERATURE REVIEW

2.1. Autism Spectrum Disorders

2.1.1. Diagnosis

Autism Spectrum Disorders (ASD) are Pervasive Development Disorders (PDD) causing impairments in communication and social interaction, and repetitive and stereotyped behaviour, interests and activities (American Psychiatric Association, 2000; Peeters, 1998). According to the PHIS Report (2001), the prevalence is approximately 60 per 10,000 children in Scotland. The concept of spectrum reflects the heterogeneity among individuals and the different forms of autism: classic autism (or Kanner's autism), Asperger syndrome and atypical autism (World Health Organisation, 1992). The triad of symptoms is the core criteria for the diagnosis of autism. However, the domains of communication and social interaction are so closely related that it could be considered as a dyad of symptoms:

- Qualitative and quantitative impairments in communication and social interaction:
 - Absence or delay of verbal language
 - Alteration of the ability to start, sustain, or finish a conversation
 - Stereotyped and repetitive use of language (e.g. echolalia)
 - Absence of symbolic play and social imitation
 - Difficulties in verbal behaviours (e.g. eye contact, gestures, facial expressions)
 - Alteration of joint attention (sharing interests)
 - Alteration of relations with peers
 - Absence of social or emotional reciprocity
- Repetitive and stereotyped behaviours, interests, and activities:
 - Excessive preoccupation for one or several limited subjects
 - Compulsive attachment to routines and non functional rituals
 - Stereotyped and repetitive motor particularities
 - Persistent preoccupation for parts of objects (Peeters, 1998).

Sensory and motor disorders are experienced by many people with autism, according to the literature and to the author's experience (Ayres, 1979; Bogdashina, 2003; Crane, Godard & Pring, 2009; Green, Ben-Sasson, Soto & Carter, 2012). The prevalence of sensory processing in people with ASD may be 80-90% (Shaaf & Miller, 2005). Sensory processing disorders can concern visual, tactile, auditory, olfactory, gustative, proprioceptive and vestibular senses (Ayres, 1979; Bogdashina, 2003; Kern et al., 2007). They are so common among individuals with autism that the DSM-V Work Group has recommended that they are considered as one of the diagnostic criteria (Mayes, & Calhoun, 2011). Many individuals with ASD have also been found to have motor difficulties: global and fine motor skills, praxis, eye-hand coordination, bimanual coordination, posture, and muscular tone (Ayres, 1979; Dowell, Mahone & Mostofsky, 2009).

Moreover, many people with ASD have additional overlapping conditions, e.g. learning difficulties, ADHD, Down syndrome, epilepsy, behavioural, dietary, sleeping, or psychiatric disorders. Therefore, professionals often have to deal with the complexity of a dual or poly-diagnosis, and need to consider each individual with his own particular needs.

2.1.2. Cognitive theories of autism

Since the last descriptions of autism, a range of theories have been produced in order to understand this particular disorder, its causes and its symptoms. The first theories were psychogenic, and pointed the mothers as the cause of their child's autism, accusing them of being "refrigerator mothers". Nowadays, these theories have been rejected, and research tends to focus on the cognitive and affective aspects (Rajendran & Mitchell, 2007).

People with ASD have a lack of **Theory of Mind** (ToM), which is the ability to consider and understand other people's mental states (Rajendran & Mitchell, 2007). This is related to a lack of **self- and others-awareness**: our ability to understand the actions and emotions of others involves the mirror neurone system, activated when

we observe other peoples acting or experiencing the same emotions or situations (Fonagy et al., 2007; Lombardo et al., 2010). But this is a difficult process for people with ASD who perceive the world in a different way. This lack of ToM prevents people with autism from understanding communication and social interactions; for example many of them find impossible guessing and considering the intention of their communication partners in order to understand the meaning of a message. This theory explains the communication impairments of people with ASD; however, its definition still needs to be agreed after 20 years of research (Rajendran & Mitchell, 2007).

Autism is also characterised by a **Central Coherence Deficit**: people with ASD have a great attention to details, but have difficulties considering the global whole (Rajendran & Mitchell, 2007). It results in considerable difficulties making sense of the environment, because they focus on one particular element instead of seeing the whole picture. However, this characteristic also constitutes an advantage and contributes to the people with ASD's strength in visual processing. According to Temple Grandin (Grandin, 2006; Grandin & Johnston, 2006), people with ASD even think in pictures. Visual information seems to be indeed more easily processed by people with ASD than information from the other senses (e.g. verbal information) (Peeters, 1998). This visual strength can be used in order to compensate some other areas of impairment. For example, the use of visual supports enables people with ASD to understand the world that surrounds them. But these visual aids must be as simple and clear as possible because of the lack of central coherence. Although the Weak Central Coherence theory constitutes a very good explanation of the cognitive style of people with ASD, it can only explain some of the autistic characteristics.

Executive Function Deficits are also observed in many individuals with ASD. Indeed, they have impairments in attention, working memory, planning, decision-making, flexibility, and judgement (Rajendran & Mitchell, 2007). These issues are very impairing in daily life, as well as at school or at work. The theory of Executive Dysfunction can explain both the cognitive and motor features observed in autism;

however, its relation to the ToM is still unclear, and some people with ASD do not show any executive function deficit (Rajendran & Mitchell, 2007).

Baron-Cohen (2006; 2010) recently developed the **systemising / empathising theory of autism**. It relies on the idea that people with ASD have high systemising (the drive to analyse or construct systems; it allows to identify the structure and rules of a system and how it will behave) and low empathising skills (the drive to identify and understand others' emotions and mental states, and to respond with an appropriate emotion). Although this theory can explain all the symptoms of autism, it is very recent and not enough documented yet. Its reliability and validity are still uncertain.

2.1.3. Educational and therapeutic interventions for people with ASD

Although autism cannot be cured, it is possible to facilitate people with ASD's well-being, development and autonomy. Since the first descriptions of autism by Kanner and Asperger in the 1960s, a range of interventions has been developed in order to support individuals with ASD.

Among these approaches, the Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) and the Applied Behavioural Analysis (ABA) are probably the two most known and used global interventions (Callahan, Shukla-Mehta, Magee & Wie, 2010). The ABA is an intensive behavioural approach that aims to change the person's behaviour by acting on the environment. It relies on Skinner behavioural principles: a behaviour that is followed by pleasant consequences will be repeated, whereas a behaviour that has no consequence on the environment, or that result in unpleasant outcomes, will be avoided (Morel-Bracq, 2009); while the TEACCH is based on biological and cognitive theories. According to the TEACCH approach, the educative approach of an individual with ASD must be based on three essential points: structuring space, time, and communication (Peeters, 1998). Both interventions were found to be helpful for people with autism by several studies, however, further research is still

needed in order to prove their efficiency (Callahan et al., 2010; Jordan, Jones & Murray, 1998).

There are also some more focused interventions, such as pharmacologic treatments, which do not have any effect on the triad of impairments but can be used in order to reduce the challenging behaviours or the hyperactivity, communication systems (e.g. Picture Exchange Communication System, Makaton, speech generating devices), or sensory integration intervention, developed by Jean Ayres, an American occupational therapist. According to Ayres (1979), sensory integration is the ability to perceive, analyse and organise the information from the body and the environment and captured by the sensorial systems (olfactive, auditive, visual, tactile, gustative, vestibular, and proprioceptive systems). This process is necessary to the child development and learning. Sensory integration techniques consist in vestibular and proprioceptive stimulations (e.g. articular and vertebral compression, proprioceptive cover or vest), deep pressures (massage or specific techniques), and environmental adaptations aiming to avoid sensory overload and stress.

2.2. Occupational therapy

2.2.1. Definition

Occupational therapy is a health profession that help people maintain, gain or recover a maximal autonomy in their daily life.

The purpose of occupational therapy is to enable people to fulfil, or to work towards fulfilling, their potential as occupational beings. Occupational therapists promote function, quality of life and the realisation of potential in people who are experiencing occupational deprivation, imbalance or alienation. They believe that activity can be an effective medium for remediating dysfunction, facilitating adaptation and recreating identity (College of Occupational Therapists, 2009, p.1).

In this purpose, occupational therapists are entitled to assess the capacities, incapacities, and disability situations of the person, through evaluations of the sensory and motor functions, the cognition, the social participation, the autonomy in the activities of daily living, and the environment. They have a very global view of the person, which enable them to consider all the aspects of their patients, and thus to elaborate personalised and adapted programmes of intervention.

The title ‘occupational therapist’ is protected by law under the Health Act 1999 (Great Britain Parliament) in the UK, and under the Decree n°86-1195 (Ministère des affaires sociales et de l’emploi) in France. In the UK the profession is regulated by the Health Professions Council (HPC), which means that all the occupational therapists working in the UK must be registered with the HPC in order to be able to practice and to use the title ‘occupational therapist’ (College of Occupational Therapists, 2010).

In the UK, a referral may be needed in order to access occupational therapy services. Some occupational therapists require a referral from a health or educational professional, whereas some others accept referrals from the person himself, a family member, or a friend. An occupational therapist can be contacted directly in order to request an assessment, which will determine whether the individual is eligible for support from an occupational therapist. In France a medical prescription is necessary to access occupational therapy services.

2.2.2. Role of occupational therapy for individuals with ASD

People with ASD are generally addressed to an occupational therapist because of their sensory and motor difficulties, their lack of autonomy in the activities of daily living, and/or for environmental adaptations.

The first stage of the occupational therapy intervention is an assessment of the abilities and inabilities of the person, as well as the needs and expectations of the person and/or the family, through an interview of the person and/or the family, and

through the conduct of formal evaluations (using standardised assessment tools or not). Occupational therapists are likely to evaluate the sensory processing (visual, tactile, auditory, olfactory, gustative, proprioceptive and vestibular senses), the motor skills (e.g. global and fine motor skills, eye-hand coordination, bimanual coordination, praxis, balance, posture and muscular tone, handwriting), the autonomy in the activities of daily living (showering/bathing, dressing, feeding, continence, and ambulation), the autonomy in the instrumental activities (e.g. school, work, and leisure activities, using public transports, driving, house work, managing money, administrative formalities, medication), the environment (e.g. home, school, workplace), and the executive functions (working memory, time and space orientation, adaptability, planning, problem solving, decision-making) of the individual with autism. The assessment process is essential to determine the needs of the person, as well as the goals and the priorities of the intervention.

Studies regarding the nature of occupational therapy interventions provided to children with ASD are rare. Occupational therapists mainly use sensory based, and skills based interventions (cognitive skills, social skills, behaviour, play, self care) (Case-Smith & Arbesman, 2008; Watling, Deitz, Kanny & McLaughlin, 1999). The nature of the intervention can vary quite a lot, depending obviously on the individual's needs, objectives and expectations, determined by the assessments and an interview of the individual and/or the family, but also on other factors such as the workplace of the occupational therapist, and the cultural context. Indeed, in the UK occupational therapy for children with autism is mainly focused on sensory integration, motor skills, the autonomy in the activities of daily living and instrumental activities, and on adapting the environment of the person. In France occupational therapists are more likely to use play therapy, educative interventions such as the ABA or the TEACCH, play therapies such as the floor time, or skill-based interventions (e.g. social skills or cognitive skills) too. As many children with ASD experience motor impairments resulting in handwriting difficulties, some of them are taught touch-typing (typing on a computer keyboard without looking at the screen or the keyboard) in order to improve their ability to take notes at school.

2.3. Evidence based practice

Evidence-based practice aims to transfer the knowledge drawn from the research literature to the practice of care provision, and to base service delivery on evidences for the efficacy of the methods employed. Following a diagnosis of autism, the diagnosed persons, their relatives and the professionals want effective interventions. However, some interventions, such as occupational therapy services, are not evidence-based (Scottish Intercollegiate Guidelines Network, 2007). The Medical Research Council (2001) placed an emphasis on the need for scientific evaluation of the treatments and interventions provided to individuals with ASD. Moreover, the number of individuals diagnosed with ASD and requiring service provision has increased a lot, and the educational field stresses the need for determining the treatments and interventions that are based on evidences for their efficacy (Odom et al., 2005).

Research studies into the benefits of occupational therapy for people with autism are rare. This may be due to the fact that occupational therapy is a relatively recent field compared to medicine or psychology that have a long tradition of research (Schaaf & Miller, 2005). Schaaf, Benevides, Kelly and Mailloux-Maggio (2012) conducted a research into the feasibility, safety, acceptability and fidelity of an occupational therapy intervention using sensory integration techniques. All the parents of the children with ASD who received the treatment indicated that they were 'very satisfied' with the intervention, and that it helped them deal with the challenges they faced in their daily life. Case-Smith and Arbesman (2008) did a literature review of research studies regarding the evidence for the outcomes of interventions used in or of relevance to occupational therapy with individuals with ASD. Several studies found that sensory integration intervention increased the ability to modulate arousal, the social interactions, the adaptive responses, purposeful play, and decreased the hypersensitivity. However, all these studies employed small sample size and lack of control groups; therefore, the evidence remains weak. According to Shaaf and Miller (2005), over 80 studies investigated the outcomes of sensory integration therapy, but only half of them showed the efficiency of the treatment. Sensory-based

interventions (e.g. therapeutic touch, massage, brushing) were found to decrease tactile sensitivity, maladaptive behaviours, hyperactivity, stereotypic movements, and to increase attention (Case-Smith & Arbesman, 2008). The evidence for the effectiveness of therapies using the auditory system (i.e. therapeutic listening and auditory integration training) was found to be weak and inconclusive. Another study by Dawson, and Watling (2000) also concluded that sensory integration intervention and auditory integration training were not well validated. Relationship-based, interactive interventions seem to have a positive impact on the communication and social interaction skills (Case-Smith & Arbesman, 2008). Children who had benefited from developmental skill-based programmes, such as the TEACCH that fits easily in the occupational therapy intervention, did progress in imitation, fine and gross motor skills, coordination, and cognitive performance, according to some studies. However, the evidence for efficacy remains weak. Social-cognitive skill training was found to have positive effects on the ability to solve problems, the emotional understanding, and social interaction, but there was a lack in evidence too. Although parent-mediated approaches appeared to reduce the level of parental stress, and to increase their self-esteem and confidence, they have mixed evidence for its effectiveness. Intensive behavioural interventions seemed to result in good outcomes for children with autism, who showed higher levels of IQ, visuo-spatial, and language development, and less challenging behaviours.

In conclusion, the evidence for the efficiency of interventions used in, or of relevance to occupational therapy remains weak and need further research. One way to conduct research into evidence-based practice is to look at the social validity, which can be defined as the satisfaction of service consumers and providers with the goals, procedures, and outcomes of the interventions. Therefore, this study aimed to give an insight into the opinions of service users and providers about occupational therapy interventions that are provided to individuals with ASD. Do they perceive occupational therapy as beneficial for people with autism? Why do they think it is or not beneficial?

CHAPTER 3: METHODOLOGY

3.1. Design

The literature review showed that the evidence on the effectiveness of occupational therapy for people with ASD remained weak. Therefore, data were collected using surveys and a cross-sectional design in order to determine whether services users and providers perceived occupational therapy as beneficial for individuals with ASD and why. In this purpose, adults with ASD, family members of individuals with ASD, and occupational therapists working with people with ASD were invited to answer a questionnaire about their experience and their opinion of occupational therapy interventions provided to people on the spectrum.

3.2. Justification

Conducting an experimental study about the outcomes of occupational therapy is difficult because of the individual nature of the work of an occupational therapist. Indeed, they usually work with individuals on a one-to-one basis, sometimes in small groups, and very rarely with large groups of individuals (Watling, Deitz, Kanny & McLaughlin, 1999). Moreover, the autism spectrum covers a huge variety of individuals who experience different types of difficulties, and who have different needs. It is therefore very complicated to empirically measure the outcomes of an intervention provided to individuals with ASD. Thus, the research into evidence-based practice tends to rely more and more on case studies and assessment of the social validity, which can be defined as the satisfaction of consumers and providers with the goals, procedures, and outcomes of the interventions (Forehand, Wells & Griest, 1980; Wolf, 1978). The concept of social validation has its roots in applied behaviour analysis, but it has then been extended to other fields. One of the ideas upon which it relies is that the statistical measure of the outcomes does not mean that a meaningful change happened for the client and their relatives (Foster & Mash, 1999). It is important to show whether the intervention has made a significant difference in the person's quality of life. In this purpose, one of the methods used by

researchers involves subjective evaluations by the clients, their families or significant others, or by experts or representative judges. For example, they can be asked to rate the client's performances in diverse areas before and after the treatment, or to express their degree of satisfaction with the outcomes (Foster & Mash, 1999).

Therefore, a survey-based design seemed very relevant to the topic of the research, and three online questionnaires were developed and addressed to individuals with ASD, families, and occupational therapists. Perhaps gathering subjective data seems less scientifically reliable; however, it allows a better understanding of people's views and opinions of occupational therapy. Indeed, it allows not only to evaluate the degree of satisfaction with the occupational therapy intervention, and whether the individual progressed during the therapy, but also whether the possible progresses have been meaningful in this person's life, i.e. whether they have led to significant changes in this person's life and quality of life. This research method was therefore preferred in order to assess how service users and providers perceive the possible benefits of occupational therapy for individuals with ASD.

3.3. Participants

3.3.1. Inclusion / exclusion criteria

Adults with ASD, parents or other family members of individuals with ASD, and occupational therapists having an experience of working with individuals with ASD were invited to take part in the study. People who have never had occupational therapy were also included in this research. Indeed, their participation could help to determine the limitations of occupational therapy services for individuals with ASD, for example difficulties accessing these services for geographical or financial reasons.

All the participants were adults (i.e. aged 18 and over), and having ASD does not mean that the individuals have not the capacity of giving informed consent. Furthermore, the online nature of the survey meant that only people who chose to

access the questionnaire participated. Individuals with ASD and their families are the first concerned, it seemed essential to ask them whether the intervention was beneficial for them. The occupational therapists are probably more able to give precise information about their intervention and the areas their patients progressed in, as they have a professional knowledge and assessment tools. However, they cannot perhaps see whether the progresses are maintained after intervention, and the extent in which the skills gained are generalised in everyday life.

The investigation was conducted both in France and in the UK because it allowed to double the number of participants involved, and it was easier to contact occupational therapists in France than in the UK. Indeed, a list of French occupational therapists working with people with autism was available online, thus they could be directly contacted. Moreover, as the researcher is a French occupational therapist currently living and studying in Scotland, therefore she was able to recruit people in France, to translate the materials into French, and she was aware of the cultural differences that may influence the results of the study. Particular differences were not expected between the French and British responses, excepting some small differences due to the cultural contexts. Furthermore, it was clear whether a participant had completed a French or English questionnaire, thus it was possible to compare the results from the two groups of respondents. One example of difference that was expected is that in France, occupational therapy is not refunded by the national health insurance if the occupational therapist works as a private practitioner. Therefore, French respondents are likely to mention financial issues as a barrier to access occupational therapy services. Another example concerns the nature of the intervention. In France, there has been a long history and culture of psychoanalytical theories and interventions, and institutionalisation of individuals with ASD. The situation is now changing after the Council of Europe pointed out the “more restrictive definition of autism than that adopted by the World Health Organization” and condemned France for non-respect of the European Social Charter, because of the lack of access to educational services for children with ASD, and the low rate of inclusion in mainstream schools (Feinstein, 2010; Council of Europe, 2004). Indeed, in France 60 percent of children with ASD have never accessed any kind of educational support, and only 1.2 percent

are included in mainstream classes (Beauguitte, 2006). Maybe this low rate of inclusion is due to the psychoanalytical “cultural” context: even if the psychogenic theories are probably not the most popular among professionals, the support of children with autism is still mainly delivered by paedo-psychiatric units of hospitals and clinics, medico-educative institutions, and socio-medical services. According to the author’s experience, the consequence on occupational therapy is that its role can be extended to more educational activities, because the child does not have access to another form of education.

The researcher hoped for a minimum of 10 participants in each of the 3 groups (individuals with ASD / families / occupational therapists). An equal number of participants in France and in the UK was also expected. Therefore, a total number of 30 respondents was hoped. However, as the study was based on online questionnaires, it was difficult to predict the number of responses.

3.3.2. Recruitment methods

An appeal for participants was advertised on the websites of the British associations ‘National Autistic Society’ (NAS), ‘Scottish Autism Network’ (previously named ‘Scottish Society for Autism’), and ‘Talk about autism’, as well as the French associations ‘Autisme 75 Ile-de-France’ and ‘Asperger Aide France’. The researcher had also planned to publish an announcement on the website of the French association ‘Autisme France’, but this service was actually reserved for the members of the association. The researcher expected these advertisement to be seen mainly by individuals with ASD and family members, but perhaps also by occupational therapists.

Emails were sent to a list of French occupational therapists working with individuals in the spectrum, available on the weblog “la main tendue”, which is published by Delphine Dechambre, an occupational therapist working with individuals with ASC. All these occupational therapists have themselves sent their contact details to Delphine Dechambre in order to appear on the list, which is publicly accessible. The

emails informed these occupational therapists about the context and the topic of the research, and asked them whether they were interested in answering a questionnaire. A link to the participant information sheet was also provided to them.

Yahoo!® Groups is a community functioning like a forum: all the messages sent to a whole group appear on the website as discussions in a forum, and members can choose to receive each message, day/week digests only, or to not receive anything in their mailbox. It counts lots of French and British groups for individuals with ASD, their family members, and/or professionals. Subscriptions and messages are moderated or not depending on the groups. The groups that clearly indicated in their description that professionals were welcomed were preferred. When subscription was moderated, the message sent by the investigator to the moderator clearly explained that the concerned group would be used in order to advertise an appeal for participants in a survey. The following groups were joined in order to communicate the appeal for participants:

- “ergo_francophone” (“French-speaking occupational therapists”) is a very active community of occupational therapists who want to share ideas and solutions. Students in occupational therapy often use this group to present and advertise their research project.
- ‘ergo_pédiatrie’ is group of French occupational therapists working in paediatrics.
- ‘autisme’ is a French group of people who want to share about autism.
- ‘La Voix de l’Enfant Autiste’ (‘The voice of the child with autism’) is the group of the association ‘Vaincre l’autisme / Léa pour Samy’.
- ‘Asperger Aide’ is the group of the association ‘Asperger Aide France’.
- ‘occupationaltherapyuk’ is a group of occupational therapists from the UK. However, this group seemed inactive (almost all the messages posted in this group were commercials).
- ‘Autism_UK’ is a support group for individuals with ASD and families.
- ‘AutismUK’ is a group created by a parent of a son with ASD and a student in psychology who plans to specialise in ASD. The group is intended for discussions and support about all the issues regarding ASD.

One of the French occupational therapists contacted also offered to transfer the appeal for participants to the association ‘Union France Sud-Est’, where she was a member.

RECRUITMENT METHODS		Adults	Family	OT	
UK	National Autistic Society	x	x	?	
	Autism Network Scotland	x	x	?	
	Talk about autism	x	x	?	
	Yahoo Groups	occupational therapy uk			x
		Autism_UK	x	x	?
		AutismUK	x	x	?
autism_parents_uk			x		
FRANCE	Weblog ‘La Main Tendue’ (list of OTs)			x	
	Autisme 75 Ile-de-France	x	x	?	
	Union Autisme Sud-Est	x	x	?	
	Yahoo Groups	ergo_francophone			x
		ergo_pédiatrie			x
		autisme	x	x	?
		La Voix de l’Enfant Autiste	x	x	?
		autisme et bonnes pratiques	x	x	?
	Asperger Aide	x	x	?	
TOTAL		11	12	≥4	

Table 1: Recruitment methods

The different recruitment methods employed, as well as the groups of potential participants targeted, are summarised in a table (table 1). It shows that there were 11 ways to contact individuals with ASD, 12 for family members, but the number of ways to contact occupational therapists (OT) was very uncertain. Indeed, there were only 4 ways to contact occupational therapists, but as some occupational therapists could be members of some associations, or of some groups of Yahoo!® Groups, the researcher thought that some occupational therapists would perhaps see the

advertisement on these websites. Moreover, the table also shows that it was very difficult to contact British occupational therapists. Indeed, the Yahoo group ‘occupational therapy uk’ seemed inactive, and although the investigator hoped that some occupational therapists would see the advertisement on the websites of the National Autistic Society, Autism Network Scotland, Talk about autism, or in Yahoo!® groups, there was no other way to contact British occupational therapists.

3.4. Materials

Three different questionnaires were created: one for adults with ASD, one for family members, and one for occupational therapists. Moreover, each of them was available both in English and in French. The French questionnaires were an exact translation of the English ones; the questions were exactly the same. The questionnaires for individuals with ASD and family members were almost the same, excepting the first question, which asked family members what was their relationship to the individual with ASD (e.g. parent, sibling, etc.). For more clarity, and considering the difficulties in communication experienced by individuals with ASD, the investigator chose to make separate questionnaires for adults with ASD and family members. The questionnaire for occupational therapists was a little bit different, but the researcher tried to keep it as similar as possible in order to facilitate the data analysis, and especially in order to be able to compare the results obtained with those of the other questionnaires. The first part was really different as it asked the occupational therapists about their training, experience, and context of working. These questions were not asked to adults with ASD and family members because it was assumed that they would probably not know this information. The following questions were very similar to those of the two other questionnaires, excepting occupational therapists answered the questions about their patients with ASD in general, and not about one particular individual. Multiple-choice questions were preferred in order to facilitate the data analysis, but some open-ended questions were also included in order to collect more information. Close-ended questions were employed only where required. Comment boxes were added at the end of the questionnaires in case

respondents wanted to specify, add, or comment anything regarding the survey and the topic of the study.

Participants were asked to fill in an online questionnaire about their experience of occupational therapy services for individuals with ASD. All questionnaires were fully anonymous, and no personal or invasive question was asked. Moreover, it was possible to quit the survey at any time until the answer was submitted. Questions asked were about the concerned individuals with ASD (e.g. age, diagnosis, eventual co-occurring condition), the training and the experience of the occupational therapist (only in the questionnaires for the occupational therapists), the characteristics of the therapy (e.g. nature, place, and time of the intervention), the satisfaction with and the opinion of the intervention, and the possible improvements and limits. The information asked about the characteristics of the individual, the occupational therapist and the intervention aimed to identify factors that could potentially influence the results of the survey. The following questions were designed to determine whether the individuals with ASD progressed during the occupational therapy intervention, the degree of satisfaction with the intervention, and the strengths and limits of occupational therapy services.

All these questionnaires were created on the website SurveyMonkey® in order to be able to publish them online. However, it was impossible to include the participant information sheet because the text was too long, therefore the investigator created a website and included the participant information sheet and the questionnaires in it. The advertisements published on the different websites contained the link to the participant information sheet, and the links to the questionnaires were placed at the bottom of this page. It allowed to make sure that potential participants had read the information before they decided to participate or not in the study.

3.5. Procedure

Full information about the study and informed consent was provided for potential participants. Information sheets were accessed online from a link in the

advertisement. There was no consent form, as the survey was only filled in online. However, the participants were assured that participation was entirely voluntary, that they did not have to fill in every question, that they could stop filling in the questionnaire at any time, and that they had the possibility not to submit the questionnaire. However, they were also informed that once the questionnaire was submitted it was impossible to withdraw, and that by submitting their response informed consent was taken as gained. Indeed, the data were anonymous; therefore the investigators would not have been able to find the data concerning the person. Links to the questionnaires were placed at the bottom of the information sheet in order that potential participant could choose to access the survey only once they had read the information sheet.

The data were fully anonymised. The questionnaires were filled online, and no name or any other information that could allow identifying a respondent was asked. The data were stored on the website SurveyMonkey®, in a secured account, and it was only accessed by the investigator. It was destroyed as soon as the research dissertation is marked as satisfactory. No invasive question was asked, potential participants were informed about the topic and the objective of the study, what was asked to them if they decided to participate, and that they could change their mind at any moment until they submitted the questionnaire. However, the questionnaire might remind the individuals of a negative experience they had. A link to a professional website was provided in order that potential participants can access support and information about occupational therapy practice if they wish. A link to the British Association of Occupational Therapists and College of Occupational Therapists was provided to British respondents, and a link to the “Association Nationale des Ergothérapeutes Français” (French National Association of Occupational Therapists) to the French respondents.

The survey was addressed to adults (aged 18 and over) only. However, due to the online nature of the survey it was impossible to check either the participants' age, or whether they met the inclusion criteria. It was presumed that people would not participate if they do not meet these criteria.

3.6. Data analysis

Data were analysed using a qualitative method. According to Bryman (2012), qualitative research, unlike natural sciences and positivism, aims to draw explanations from people's experiences and accounts.

A thematic approach was used in order to identify the points on which the respondents agreed or disagreed. Five main themes were included in the survey and emerged from the results: the characteristics of the participants, the proportion of individuals with ASD who had already had occupational therapy, the opinions of the persons who never had occupational therapy (or whose relative never had occupational therapy), the characteristics of the occupational therapy intervention, and finally the opinions of the occupational therapy intervention. The latter was designed to answer directly the research question 'Do service users and providers perceive occupational therapy as beneficial for individuals with ASD? And why do they think it is (or not) beneficial?', and included the following sub-themes: the overall opinion, the usefulness, the quality of the collaboration, whether the expectations of the patients and their families were met, the strengths, weaknesses, and limits of occupational therapy services, and whether occupational therapy should be available as core services. The other themes allowed to provide information about the context of the intervention, which could be crossed with the results obtained in the last section, and to reinforce certain topics emerging from the analysis. For example, the opinions of people who did not have occupational therapy was very interesting, and reinforced some points also introduced by respondents who did have occupational therapy: it showed that there was a lack of information about occupational therapy, a lack of service provision for adults with Asperger syndrome, and difficulties accessing occupational therapy services.

Some statistics were also used in the form of response counts and percentages in order to observe the similarities and differences between participants. It allowed to compare the experiences and opinions between the different groups (adults with

ASD / family members / occupational therapists), and between the two countries (UK / France).

However, as seen above, the research had a qualitative design, and the emphasis was given on the experiences and opinions of the people participating in the research rather than on the statistical results obtained. Indeed, occupational therapy is based on a global approach of the person, and people with ASD experience very diverse impairments. The type of intervention they receive from the occupational therapist can therefore vary quite a lot, which may result in different experiences and opinions of this intervention.

CHAPTER 4: RESULTS

4.1. Presentation of the participants

4.1.1. Number of participants

Although 27 responses were counted, one individual with ASD from the UK submitted the questionnaire without answering any question, and one family member, from the UK too, answered only one question (the age of the person with ASD at the time of the occupational therapy intervention). Therefore, these two respondents were excluded from the study, as their answers could not be analysed. Thus, 25 participants were included in the study: 9 individuals with ASD, 11 family members, and 5 occupational therapists, which was a little bit less than expected. Indeed, a number of 5 participants in each group and from each country, so a total of 30 respondents, was hoped. Moreover, the numbers of participants in the 6 different groups were very unequal. No occupational therapist from the UK, and only one French adult with ASD answered the survey.

PARTICIPANTS	UK	France	Total
Adults with ASD	8	1	9
Family members	3	8	11
Occupational therapists	0	5	5
Total	11	14	25

Table 2: Number of participants per group and per country

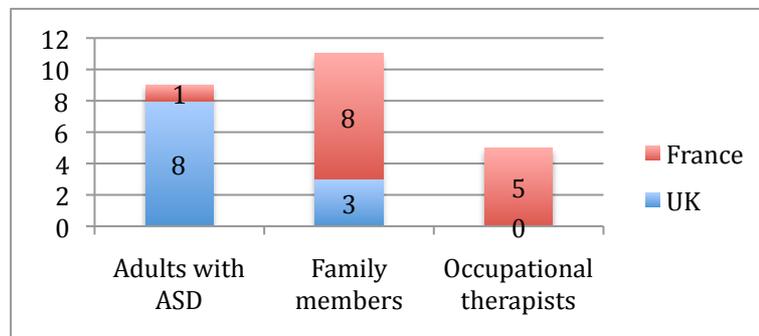


Figure 1: Repartition of the respondents

4.1.2. Adults with ASD

The nine adults with ASD who answered the questionnaires were aged from 25 to 50 years, with an average of 38.5.

Almost all of them were diagnosed with Asperger syndrome (88.9%), excepting one who had classic autism (11.1%).

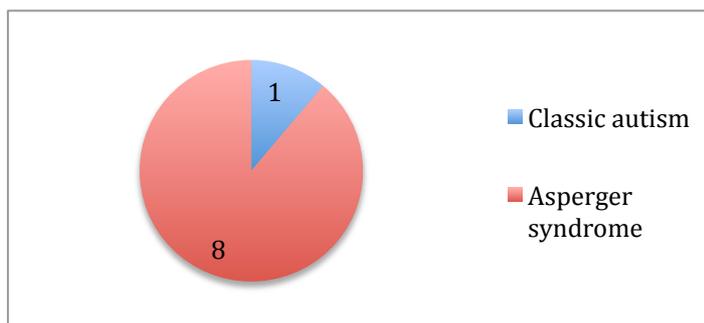


Figure 2: Diagnoses of the adults with ASD participating in the study

Only one did not have any co-occurring condition. The eight other ones (88.9%) described very diverse disorders: depression, anxiety, dyspraxia, dyslexia, epilepsy, attention deficit, obsessive compulsive disorder (OCD) complex posttraumatic stress disorder (PTSD), borderline personality disorder, dissociative disorder, asthma, Crohn's disease, and chronic migraines. Depression was mentioned by three people, attention deficit by two persons, whereas the other conditions were mentioned only once.

4.1.3. Family members

Six (82%) of the eleven family members who participated in the study were a parent, one (9%) was a sibling, and one (9%) was a wife of a person with ASD (Graph 2).

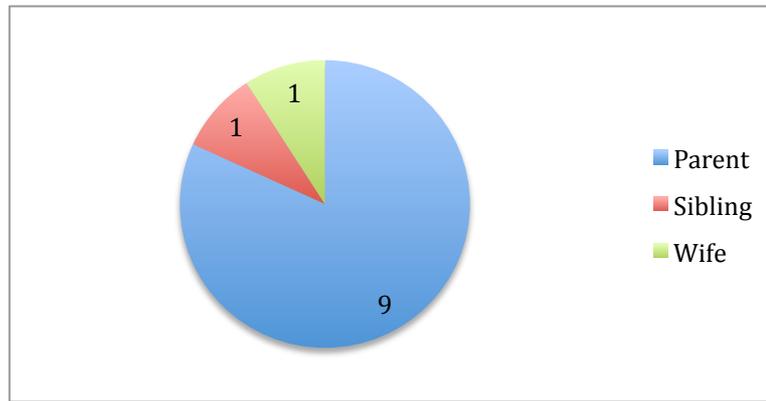


Figure 3: Relationship to the individual with ASD

Their relatives with ASD were from 2.5 and 31 years old, with an average of 11.5. A significant difference was found between the UK and French responses: the average for the UK participants was 3.5 years old, whereas it was 14.5 for French respondents. Even if the responses given by parents only were counted, the average was 3.5 for the UK respondents, and 11.9 for France.

Four of their relatives with ASD were diagnosed with classic autism (36.4%), three with Asperger syndrome (27.3%), and one with high-functioning ASD (HFASD) (9%). One other respondent was waiting for the official diagnosis but had been said high-functioning ASD too. Two French participants were given different diagnoses: ‘Pervasive Development Disorder of an autistic type’ and ‘autistic syndrome’.

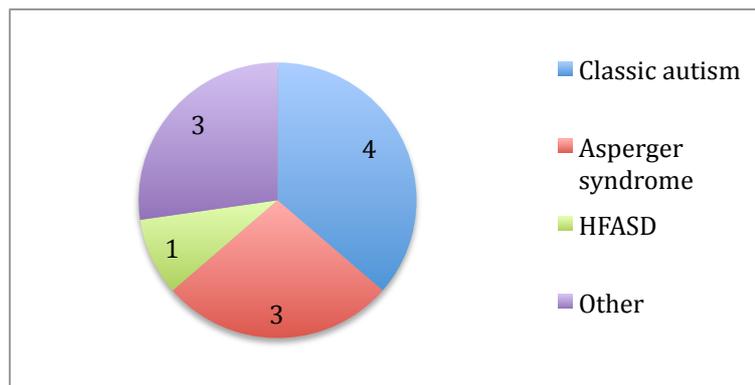


Figure 4: Diagnoses of the relatives of family member respondents

Three family members answered their child with autism did not have any co-occurring condition, whereas the others mentioned Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD), praxis disorders, developmental coordination disorder (DCD), amblyopia, lymphatico-venous deformity, migraine, mild deafness, scoliosis, face and torso deformities.

Asperger syndrome was way more common among the respondents with ASD than among the people with ASD family members described. It seems logical, as the nature of the survey implied that the individual had to be able to access it online. Attention deficits were mentioned by six respondents (ADHD/ADD), and motor disorders by three people (dyspraxia, DCD, praxis disorders).

4.1.4. Occupational therapists

All the occupational therapists taking part in this research were French. They had from 1 to 11 years of experience of working with people with ASD, with an average of 3.9.

Only 1 (20%) occupational therapist had only the French diploma of occupational therapist, whereas the 4 other ones (80%) had undertaken additional courses (initial or continuing training). Indeed, the first one was trained to the Picture Exchange Communication System (PECS), the Applied Behavioural Analysis (ABA), concrete communication, and sensory disorders. The second one had undertaken training courses in communication and multiple disability, autism and associated disability, disability and communication, and computing and intellectual disability. The third occupational therapist studied a ‘Diplôme Universitaire’ (university diploma) in autism, which is a diploma delivered by a university (while the other diplomas are usually delivered by a ministry). The fourth occupational therapist was trained to the PECS and to the sensory integration intervention.

Three of them (60%) worked full time, whereas the two other ones (40%) worked part time: half-time or quarter-time. The average work time percentage (full-time

equivalent) was 75%, which equals 26.25 hours of work per week (full-time work is 35 hours a week in France).

Two (40%) of the occupational therapists work with individuals with ASD only. One had between 80 and 100% of his patients who had ASD, another one from 50 to 80%, and the last one less than 50%. When asked about the sector they worked in, three mentioned the associative sector, two the public sector, and one the private sector (OT4 work both in the associative and private sector).

None of them worked with pre-school children, four of them (80%) worked with school-aged children, three (60%) with adolescents, and two (40%) with adults.

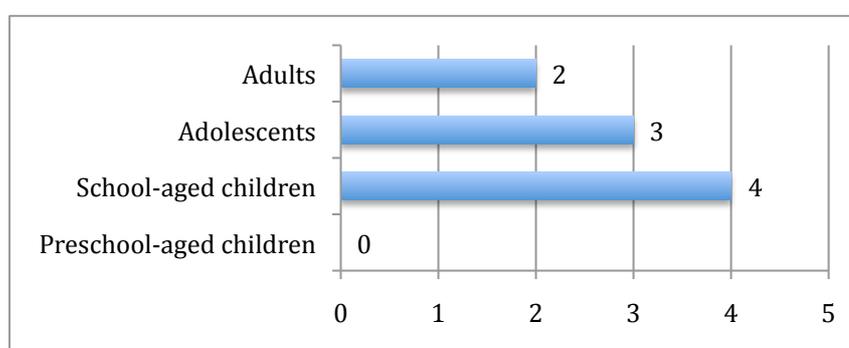


Figure 5: Age of the patients

The five occupational therapists (100%) worked with individuals with classic autism, one with people with Asperger syndrome (40%), two with persons with High Functioning ASD (40%), and three (60%) with other diagnosis (Pervasive Development Disorders, ‘autistic disorder with associated sensory defences’, ‘multiple handicap with autistic disorders’). From the investigators’ experience as an occupational therapist, it is common in France to work with children of adults who have been identified as being on the autistic spectrum, but who do not have an exact diagnosis corresponding to a type of autism described in the international classifications (DSM-IV or ICD-10).

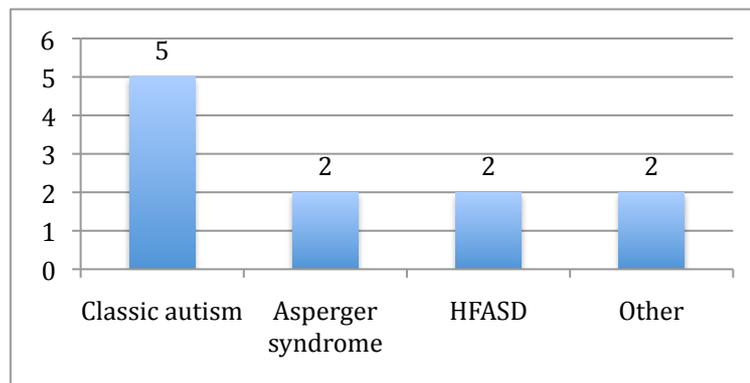


Figure 6: Diagnoses of the patients

Only one occupational therapist declared his patients did not have any co-occurring condition. The four other ones mentioned ADD/ADHD (mentioned four times), epilepsy, psychological disorders (mentioned twice), visual impairments, mild deafness, spastic quadriplegia, genetic diseases, conditions due to aging, and mild to severe mental retardation.

4.2. Number of individuals with ASD having had occupational therapy

Three of the nine individuals with ASD who answered the survey had already had occupational therapy (33.3%). Among the six who did never have occupational therapy, five explained the reason: two did not know about occupational therapy services, two had difficulties accessing occupational therapy services, one said ‘it was never offered’, and the last one did not know why.

Seven of the eleven family members (54.5%) reported their relative with autism had already had occupational therapy, in the past or at the time of the survey. All the family members with ASD of the three UK respondents (100%), and four of the eight French participants (50%) had already had occupational therapy. Two family members explained their relative with ASD never had occupational therapy because of difficulties accessing occupational therapy services, and one did not know why his/her relative had never had occupational therapy.

If the answers given by the two groups of respondents (adults with ASD and family members) are reassembled, half the people with ASD had already had occupational therapy, whereas the other half did not (see figure 7). Among the 10 individuals who did not have occupational therapy, 4 did have difficulties accessing occupational therapy services, 2 did not know about occupational therapy, one said it was never offered, and 2 did not know why they did not have occupational therapy. Nobody said they did not have occupational therapy because there was no need for it.

It was less common to have had occupational therapy among the adults with ASD who answered the survey than among the individuals with ASD whose relatives answered the survey. This is perhaps less common for people with Asperger syndrome to access this type of service. The results also showed that occupational therapists worked with more individuals with classic autism than with people with other types of ASD.

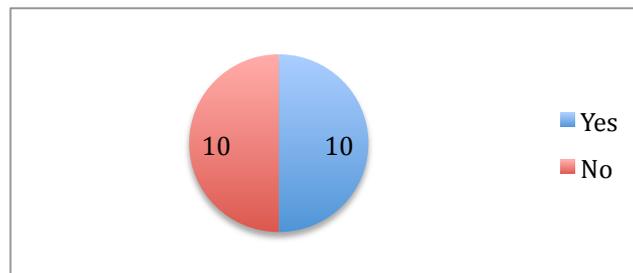


Figure 7: Proportion of individuals who had already had occupational therapy

4.3. Opinions of the persons who never had occupational therapy

4.3.1. Opinions of adults with ASD who never had occupational therapy

Two adults would have liked to have occupational therapy, the first one to have help with his/her sensory processing issues, and the second one said:

Having experienced problems gaining employment and staying in employment, I would like some sort of occupational therapy to make life easier in this area. I was only diagnosed recently and have been given very little follow up support.

The four other adults with ASD replied ‘I don’t know / no opinion’, and specified:

I can’t see how it would help me.

I don’t know how occupational therapy could help me so therefore I don’t know if I would have liked it.

Never had info on whether it would be helpful for my condition.

It might help. But I’ve asked for any help and none is forthcoming. I was referred to an AS (Asperger Syndrome) counsellor in June. I have an initial assessment in October. My GP (General Practitioner), who has AS, said there is little point in treating adults with AS as it makes no difference.

Although most of the adults with ASD who filled in the survey did not see how occupational therapy could help them, no one answered that he wouldn’t have liked to have occupational therapy. Considering their comments, it seems that there is really a lack of information about occupational therapy services, and a lack of support for adults with ASD (compared to the availability of services for children with ASD).

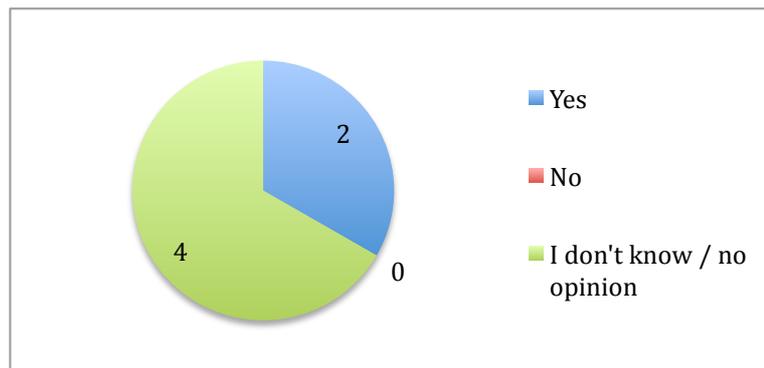


Figure 8: Would adults with ASD who never had occupational therapy have liked to access these services?

4.3.2. Opinions of family members whose relatives with ASD never had occupational therapy

Family members gave different answers: only one said he did not know whether he would have liked his relative to have occupational therapy because he did not know what was occupational therapy very well. The three other would have liked their relative with ASD to have occupational therapy to have help with sensory and motor difficulties, the autonomy in the activities of daily living, social behaviours, and to gain comfort.

One parent added he thought that occupational therapy should be included in the support of every person with autism.

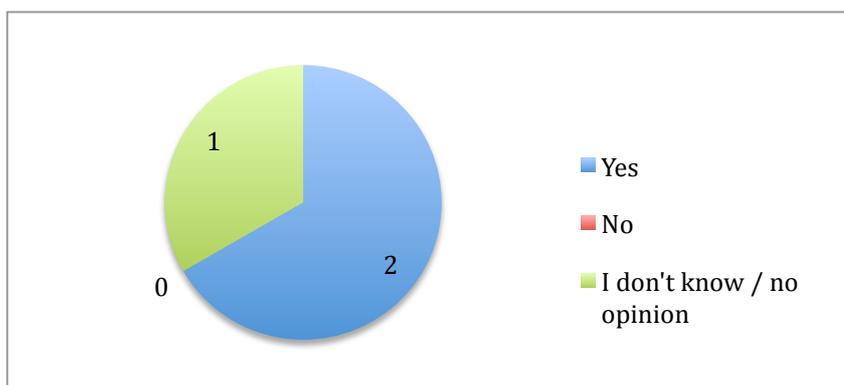


Figure 9: Would family members of individuals with ASD who never had occupational therapy have liked to access these services?

4.4. Characteristics of the occupational therapy intervention

4.4.1. Age of the individual with ASD at the time of the intervention

Two adults with ASD had occupational therapy when they were an adolescent or an adult (19 years old).

According to the answers given by family members about their relative with ASD, four of them had occupational therapy when they were preschool-aged children, one

when he was a school-aged child (8 years), and one as an adolescent (13 years). Three of the four children who had occupational therapy when they were pre-school children were British. French children who had received occupational therapy services tended to be older.

As seen before, occupational therapists participating in this research mainly worked with school-aged children, adolescents, and adults (figure 5). None of them worked with pre-school children.

The answers given by the different groups of participants were very unequal (Graph 9). Indeed, most family members of children with ASD reported their child had occupational therapy when he was a preschool-aged child, whereas no adult with ASD declared having had occupational therapy at that age, and no occupational therapist involved in this research worked with children of that age either.

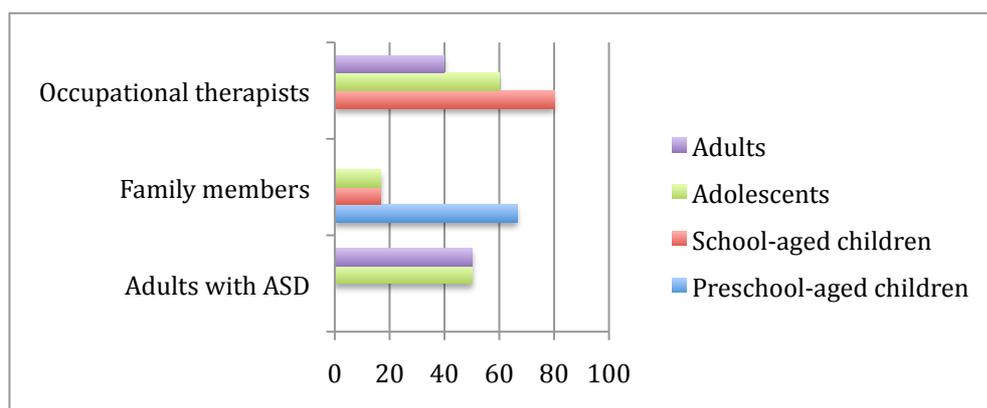


Figure 10: Percentages (%) of each age per group of respondents

4.4.2. Quantity of therapy

The duration of the therapy seemed to be very variable: from two hours (this respondent had perhaps just started the therapy) to 12 years. The duration and the frequency of the sessions were also unequal. Indeed, the sessions were reported to last from 30 minutes to 2 hours maximum, and were repeated daily, twice a week, weekly, every two weeks, or monthly. The individuals with ASD concerned by this research had consequently received very diverse amounts of occupational therapy.

French respondents described higher quantities of therapy: sessions took place at least once a week; whereas in the UK it tended to be once or twice a month, excepting one adult with ASD who had 1 or 2 hours of therapy per day, but this was only for two weeks.

4.4.3. Nature of the intervention

All the respondents reported they had seen an occupational therapist for an assessment plus an intervention, excepting one adult with ASD (A3) who did not know. No one said he had seen an occupational therapist for an assessment only.

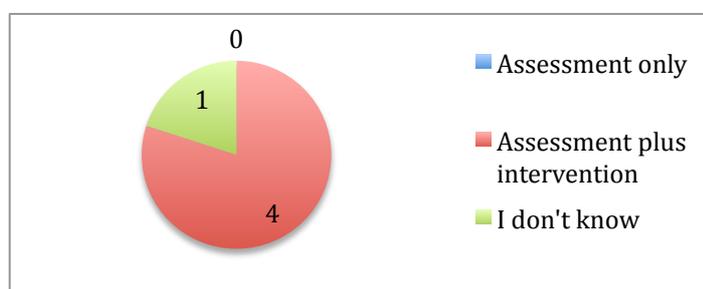


Figure 11: Assessment and/or intervention?

All the occupational therapists reported they usually assess the motor skills and the autonomy in the activities of daily living of their patients with ASD. Three of them (60%) reported they also assessed the autonomy in the instrumental activities and the environment of the person. Only two (40%) evaluated the sensory integration, and one mentioned other areas of assessments: cognitive skills, neuro-vision, and evaluations of the associated disorders (e.g. orthopedic).

Two occupational therapists (40%) reported they did not use any standardised assessment tool at all, while two others used a little bit that type of evaluation, and only one (20%) used it a lot.

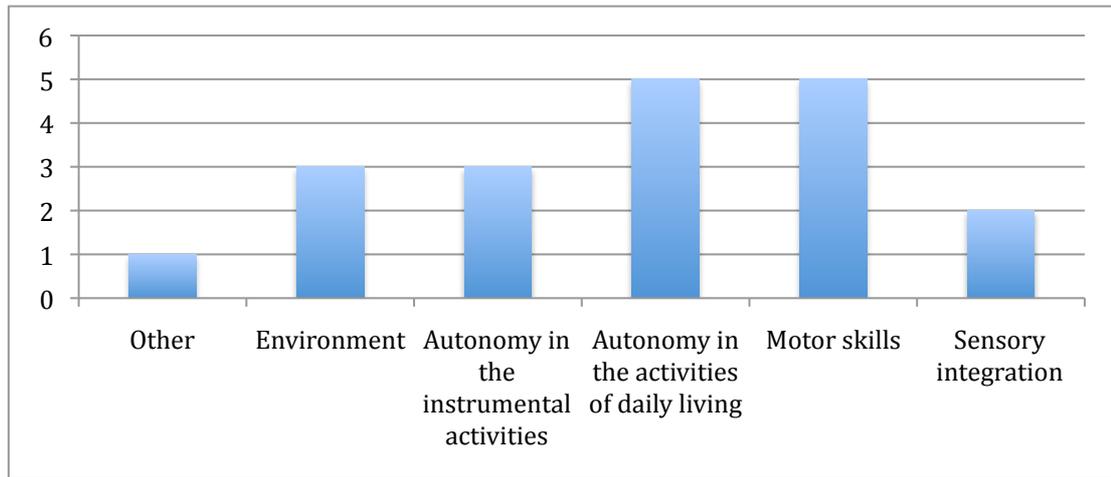


Figure 12: Assessment areas

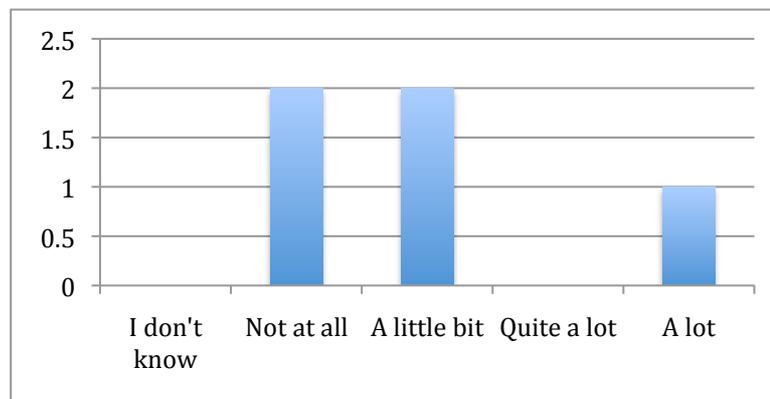


Figure 13: Use of standardised assessment tools

According to the results of the survey, the most common types of occupational therapy intervention were based on motor skills, autonomy in the activities of daily living, cognitive functions, environmental adaptations, social skills, and play therapy. However, respondents also reported the use of sensory integration intervention, intensive behavioural intervention, parent-mediated approach, touch-typing, the TEACCH, the PECS, and the ‘Thérapie d’Échange et de Développement’ (Exchange and Development Therapy, an intervention developed at the university of Tours in France, and that is based on exchange and play techniques).

No significant difference was found in the nature of the intervention provided to individuals of different ages or with different diagnosis.

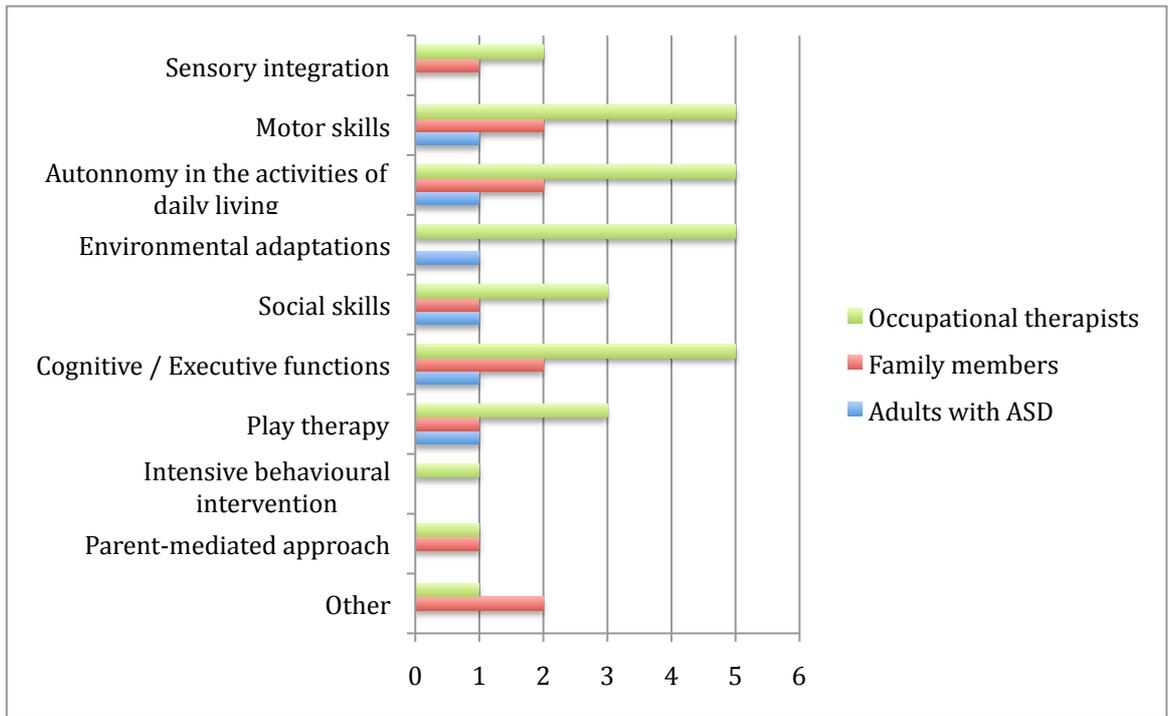


Figure 14: Nature of the intervention

4.4.4. Places of intervention

The intervention usually took place in a hospital, an institution, a school, at home, in a clinic, at the workplace of the patient, a mental health day centre, and/or a nursery. Occupational therapists were more likely to declare the intervention was provided in the context of an institution. Nobody reported provision of occupational therapy services in an independent practice.

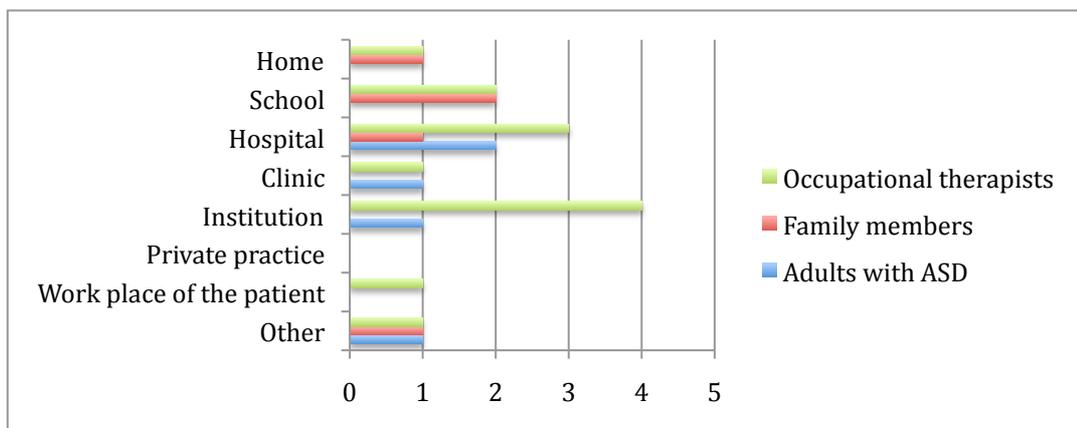


Figure 15: Places of intervention

4.4.5. Other intervention(s) provided at the same time

Three respondents, or their relative with ASD, were attending a school at the time of the occupational therapy intervention, whereas two did not.

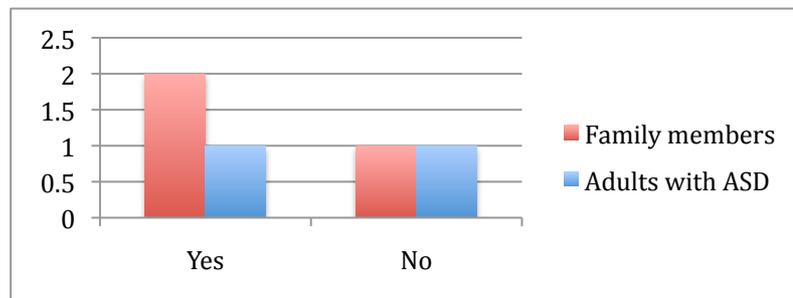


Figure 16: Did you / your relative with ASD attend a school at the time of the occupational therapy intervention?

Three occupational therapists had up to 40% of their patients who attended a school at the time of their intervention. Only one had 80% to 100% of his patients who attended a school.

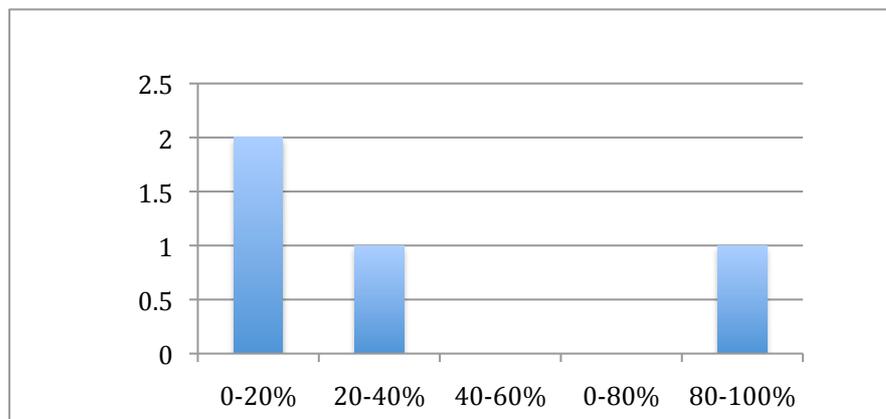


Figure 17: Percentage of patients attending a school

All the adults with ASD and persons with ASD whose family members answered this question were attending a 'typical' class in a mainstream school. Occupational therapists also worked with children who had access to specialised education.

	A 'typical' class	A class for children with various learning disabilities	A class for children with PDD	A class for children with ASD
In a mainstream school	6	1	1	1
In a school for children with special needs	0	2	0	1

Table 3: Type of school and class attended

Some of the individuals with ASD concerned by the study also received other types of educational or therapeutic interventions such as speech and language therapy, the TEACCH, the ABA, the PECS, social skills group, psycho-motricity therapy, adapted sports, psychology, follow-up by a general practitioner (GP), genetician, neurologist, neuropsychologist, nurses, and educators (in France many people with ASD, or with any type of disability, receive support from educators, who are considered as social workers).

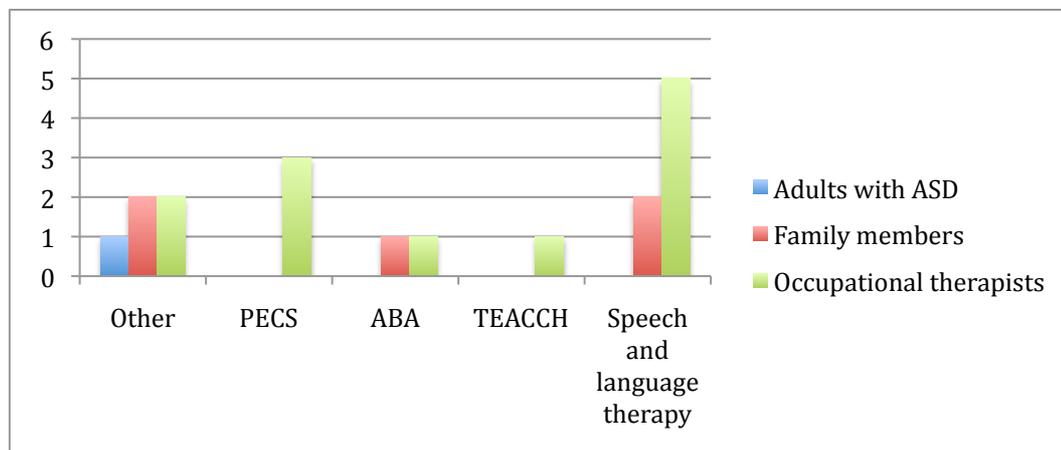


Figure 18: Other interventions provided

4.4.6. Collaborative practice

Most of the respondents reported the occupational therapist worked a lot or quite a lot in collaboration with the other professionals involved in the support of the person with ASD. However, one occupational therapist answered he did not work at all with other professionals, and two other participants responded they did not know.

Three occupational therapists told they worked a lot in collaboration with the families of their patients with ASD, whereas the two others said they only worked a little bit with the families.

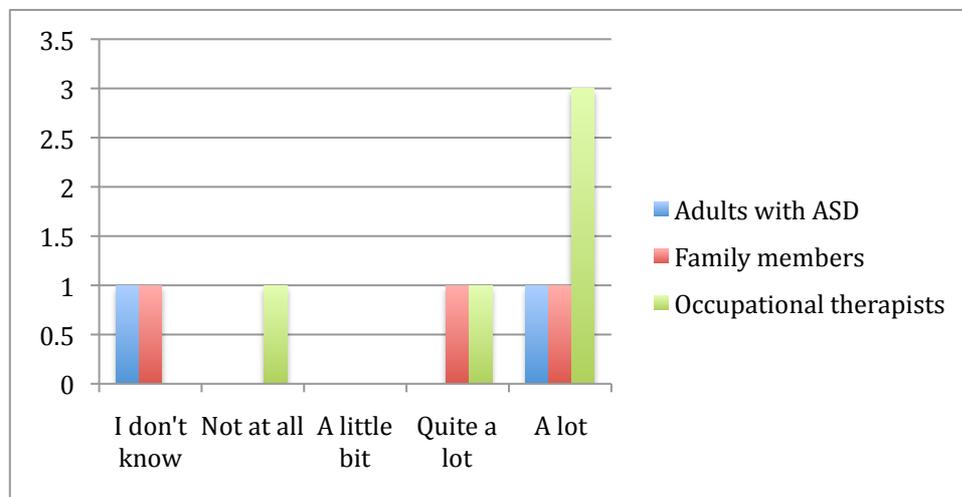


Figure 19: Collaboration with the other professionals

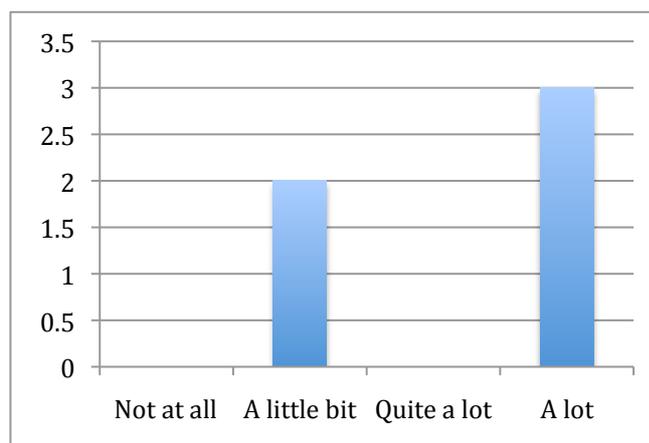


Figure 20: Collaboration between the occupational therapist and the families

4.5. Opinions of the occupational therapy intervention

4.5.1. Overall opinion

Eight participants expressed their experience of occupational therapy services was overall quite positive, and one said it was very positive.

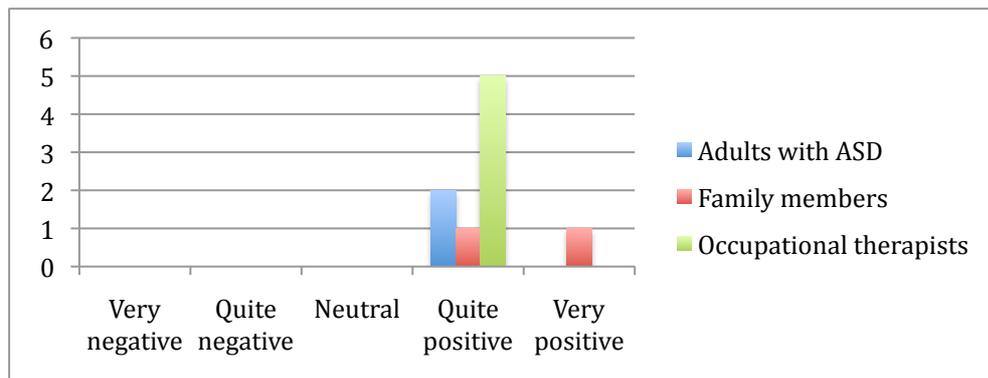


Figure 21: Opinion of the occupational therapy services received / provided

4.5.2. Usefulness

Five participants said they found occupational therapy quite useful for them / their relative with ASD / their patients with ASD. Four found it very useful, and two a little bit useful. The child whose family member found occupational therapy had been a little bit useful had only received 2 hours of therapy so far. Moreover, he was the only preschool-aged child concerned in this question. Nobody answered he did not find it useful at all.

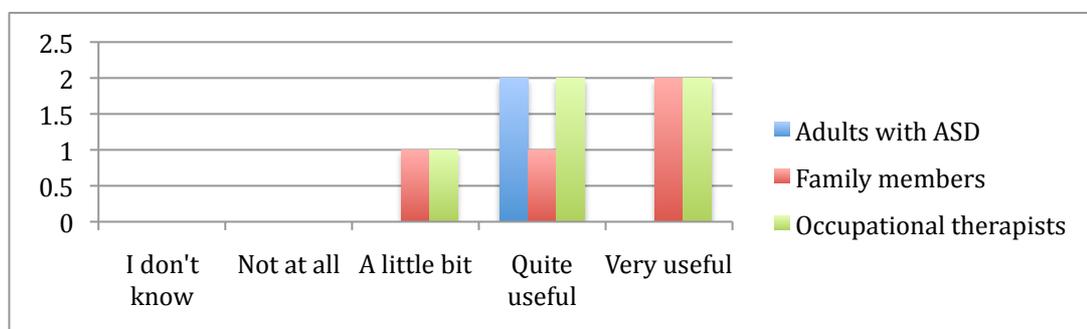


Figure 22: Usefulness of occupational therapy

The participants observed progresses in the autonomy in the activities of daily living, in motor skills, communication and social interaction, behaviour and activity, executive functions, quality of life, sensory processing, and touch-typing skills. However, progresses in sensory processing were observed by one family member only. Although 2 occupational therapists declared they used sensory integration techniques, no one or them reported progresses in this area.

OT was recommended for me after diagnosis to help with difficulties, originally thought of in relation to my malformed thumbs, but provided me with a better understanding of what the problems were related to. It provided essential help with issues related to fine and gross motor skills, balance, coordination, writing, and provided me with essential needed equipment and ideas (Adult with ASD).

One adult with ASD reported it really reduced his level of stress and increased his emotional well-being.

I was less stressed, and engaged in a better level. I was happy for a bit, which was rare (Adult with ASD).

Most respondents said these progresses were maintained after the intervention. Indeed, three participants observed they were maintained for a long time, two definitively, and two only for a short time. Three people did not know whether the progresses were maintained. Only family members reported progresses were maintained definitively. Adults with ASD found they were maintained for a short or a long time, but not definitively. Two occupational therapists did not know whether the progresses were maintained after the intervention.

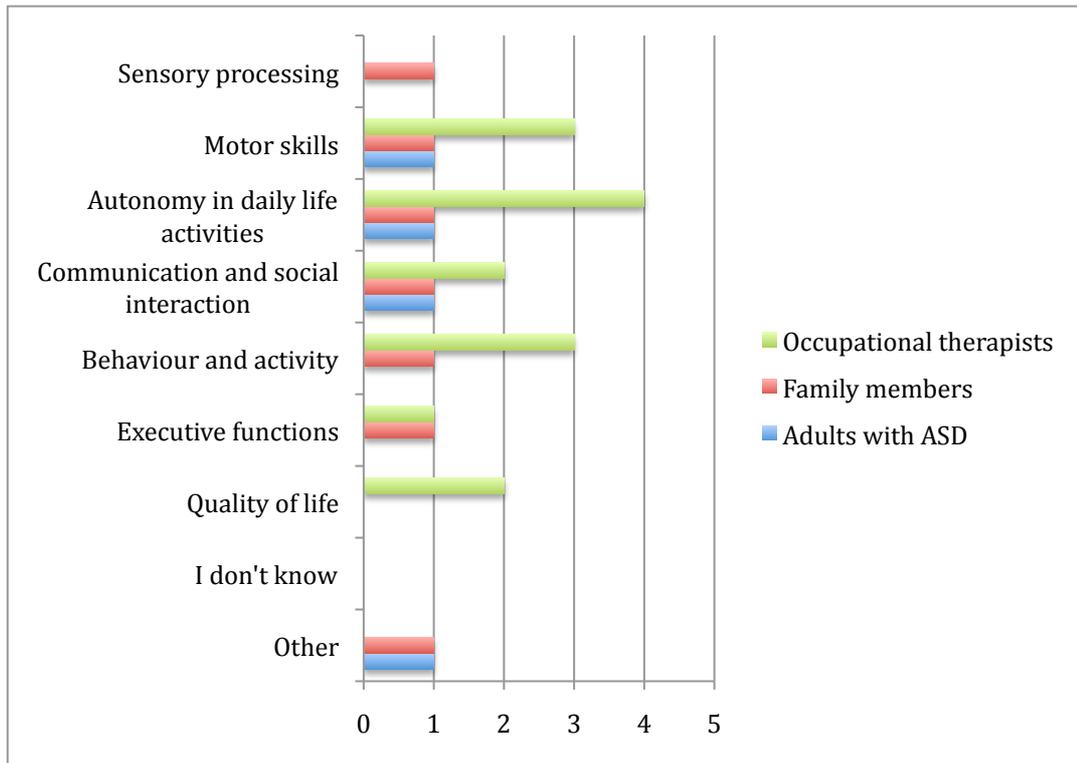


Figure 23: Areas of progress

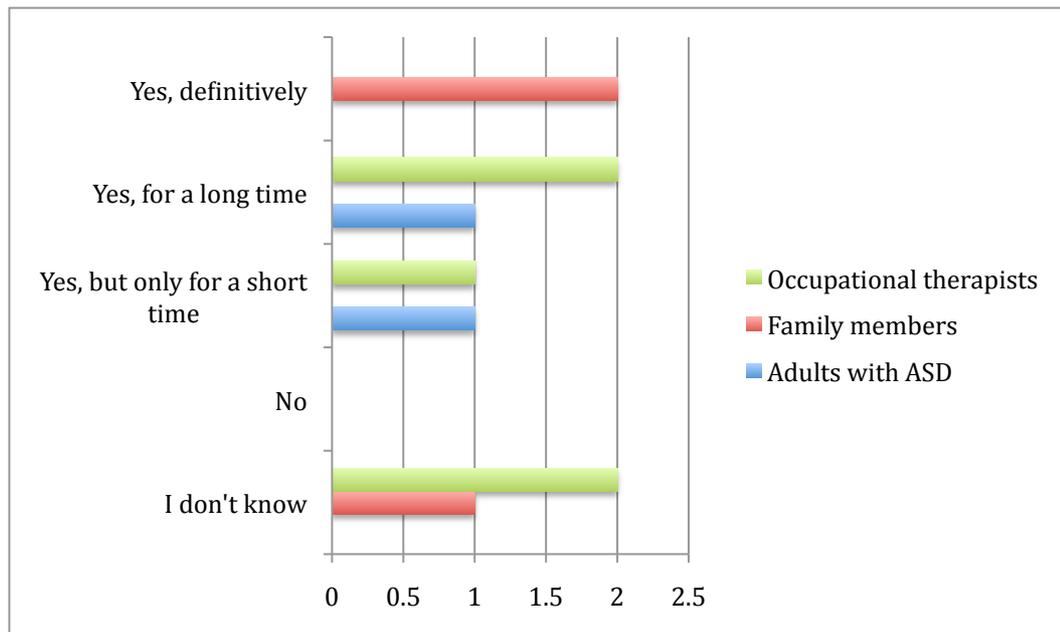


Figure 24: Maintain of the progresses

4.5.3. Expectations

Occupational therapists seemed to meet the persons with ASD's and families' expectations. Family members said the occupational therapist meet their expectations a little bit, to quite a large extent, or mostly. The preschool-aged child whose family member found occupational therapist had responded a little bit to his expectations had only received 2 hours of therapy so far. Adults with ASD answered either mostly, or that they did not know. And occupational therapists thought they met their clients' and their relatives' expectations a little bit, or to quite a large extent. No participant said occupational therapy did not meet the expectations at all.

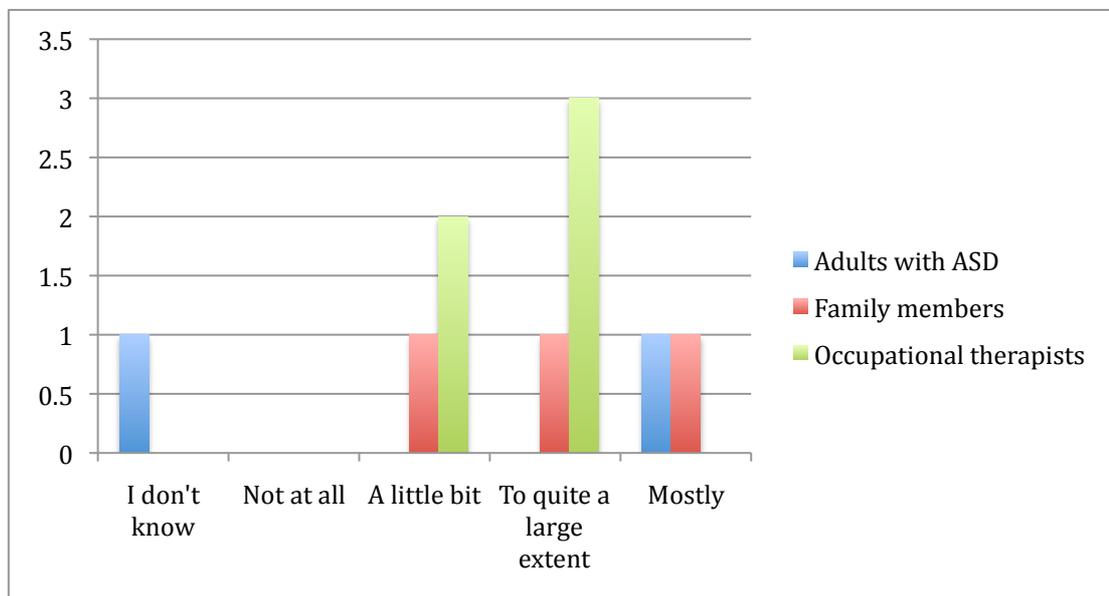


Figure 25: Did the occupational therapist meet the clients' expectations?

4.5.4. Quality of the collaboration

A majority of respondents thought the relationship and the collaboration between the occupational therapist and the person with ASD was quite good or very good. However, two participants rated it as 'neutral', and one as 'quite bad'. The person who rated the collaboration as quite bad was the one who found the therapy a little bit useful and that the occupational therapist responded a little bit to his expectations, whereas the other respondents had more positive opinions.

The opinions of the quality of the relationships and the collaboration with the families and the other professionals were more positive. Indeed, these interactions were rated as ‘neutral’ to ‘very good’, or ‘I don’t know’. However, occupational therapists seemed less satisfied with the quality of the relationship with the families than adults with ASD and family members did.

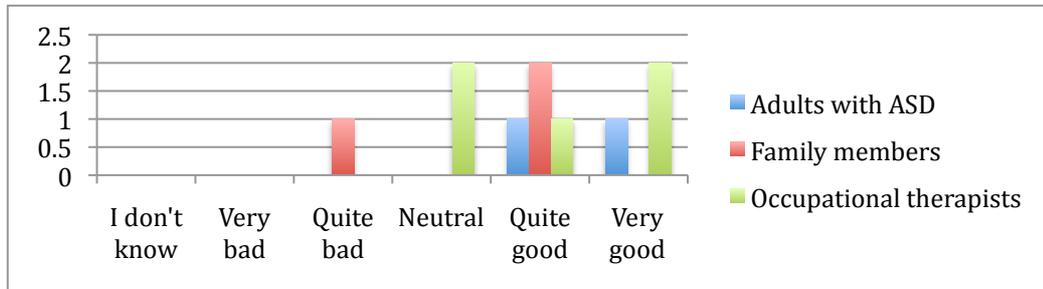


Figure 26: Quality of the relationship and the collaboration between the occupational therapist and the person with ASD

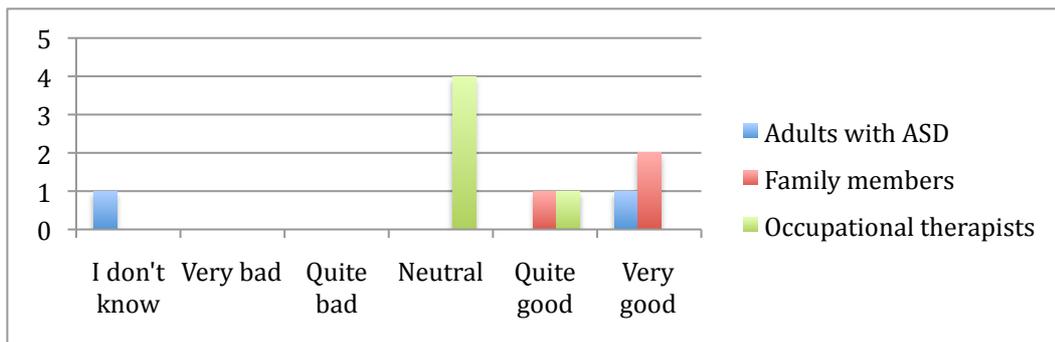


Figure 27: Quality of the relationship and the collaboration between the occupational therapist and the families

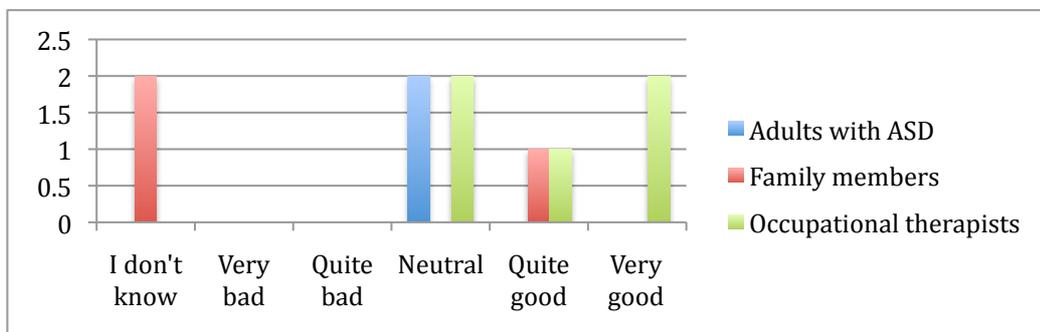


Figure 28: Quality of the relationship and the collaboration between the occupational therapist and the other professionals

4.5.5. Strengths and weaknesses of occupational therapy services

Participants in this research were asked what were the points they found especially positive, and the things they would like to change, about occupational therapy for individuals with ASD.

The most often mentioned positive points were that occupational therapy is the provision of concrete solutions and environmental adaptations, the adaptability and the personalisation of the intervention. Respondents also cited the following points: listening, concrete reference points, valorising results, progressivity, evaluative intervention, relay with the other professionals, putting the person in situation of activity in order to help develop interests, concrete objectives (including daily life), facilitation of acceptance, amelioration of skills (e.g. fine motor skills, touch typing, etc.) and of the well-being, the visual aspect of art therapy as a communication choice, and the regular stimulation.

Many respondents found that more information should be provided to the clients and their families, that a better training of the occupational therapists to the functioning of people with ASD and more specific interventions would be beneficial. Some of them also thought that the accessibility of occupational therapy should be increased, as well as the collaboration with the families and the follow-up support; and specific assessment tools should be developed. Almost all the occupational therapists also mentioned the lack of recognition of the profession, and of its ability to support individuals with ASD.

One adult with ASD expressed that occupational therapy should not be provided in the context of a large group of people with diverse mental health issues, as he felt very unsafe in this group. He also commented he thought that occupational therapy had the capacity to bridge the gap in the provision of services for adults with ASD.

OT would provide a window of service that could bridge the gap in provision for ASD adults, it has the skills and directives of a service that could provide a

safe haven for all the adults who have been overlooked and dumped out of every other service. The excuses are endless but for an ASD adult this is just another we love the kids option but it could be a starrer place for adult services as an identifier of provisions needed in the NHS as well as social services, GP understanding and financial directions of choice for the neglected adult members of the ASD community. If the issues of adult ASD are not addressed with the same vigour as the child AS then we will live out our days in pain and distress without intervention just as we have done for generations, scaring ourselves on the ignorance of our environment and alien to all that surrounds us (Adult with ASD).

Respondent	Strengths	Weaknesses
Adult with ASD	For me it helped with my related difficulties and helped my self-esteem through this. I think it's good for older children or adults as it helps better deal with certain difficulties.	Better explanations on what they are testing for. More knowledge on how things will benefit you.
Adult with ASD	Visual aspect of art therapy as a communication choice. The regular stimulation. A kind reflection and moment in life.	Not in a mixed group of large range of mental health challenges, I felt unsafe a lot with the unstable schizophrenics and violent ones who were not ASD.
Family member	Advice about calming aids, like weighted therapy.	Waiting time to see the OT. More specific interventions (the intervention for my son's PICA revolved around chewy sticks, my son however does not want to chew, he wants to ingest all sorts of inedible things, had no help really with that, they do not seem to

		know).
Family member	Amelioration of the fine motor skills. Teaching computer use.	Ameliorate the training in the functioning of persons with ASD.
Family member	Facilitates acceptance. Proposition of adapted alternative solutions.	Cannot answer this question before 6 months. (This respondent's daughter had only had a couple of sessions)
Occupational therapist	Adaptation of our techniques to people with autism (including activity analysis). Putting in situation of activity to help develop interests. Concrete objectives (including daily life).	Increase the collaboration with families. Make value our skills in supporting the development of functional communication. Accessibility of occupational therapy for people with autism.
Occupational therapist	Evaluative intervention. Environmental adaptations. Relay with the other professionals.	Follow-up support. Specific assessments. Recognition.
Occupational therapist	Concrete reference points. Valorising results. Adaptability and progressivity.	Assessment tools. Better initial training. Recognition of the profession.
Occupational therapist	Listening. Adaptation. Personalisation.	Specialisation of our knowledge. Diversification of the means. Concretisation of the progresses.

Table 4: Positive and negative points about occupational therapy services for individuals with ASD

4.5.6. Difficulties accessing occupational therapy services

A slight majority of respondents expressed difficulties accessing occupational therapy services, because of a lack of service provision in their geographical area, because of waiting list, or because of the cost of occupational therapy. This last point may be specific to France as occupational therapy is only refunded by the national insurance service when provided in the context of an institution/hospital/etc. but not in the context of an independent practice. The participants also mentioned a lack of service provision for adults with Asperger syndrome, and a lack of information about occupational therapy and how to find an occupational therapist.

This service was a potluck and an only once in a lifetime event for me, services are not provided to adults unless you have Down syndrome or a low IQ (Adult with ASD).

I had no contact, I had to look for a practitioner by myself. I think I called at least ten occupational therapists before I found someone available relatively quickly (Family member).

When a family is told their child requires therapy, a wait of up to twelve weeks for assessment only is stressful, there is no advice or recommendation if you wish to pay privately as they say it's a conflict, the parents just want to get help for their child as soon as possible (Family member).

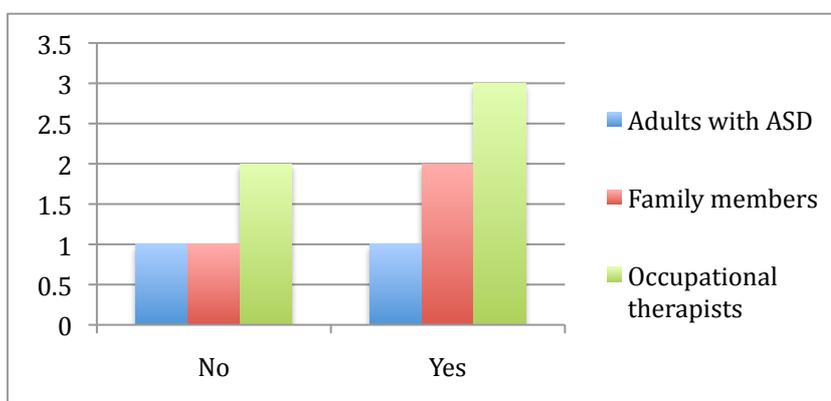


Figure 29: Difficulties accessing occupational therapy services

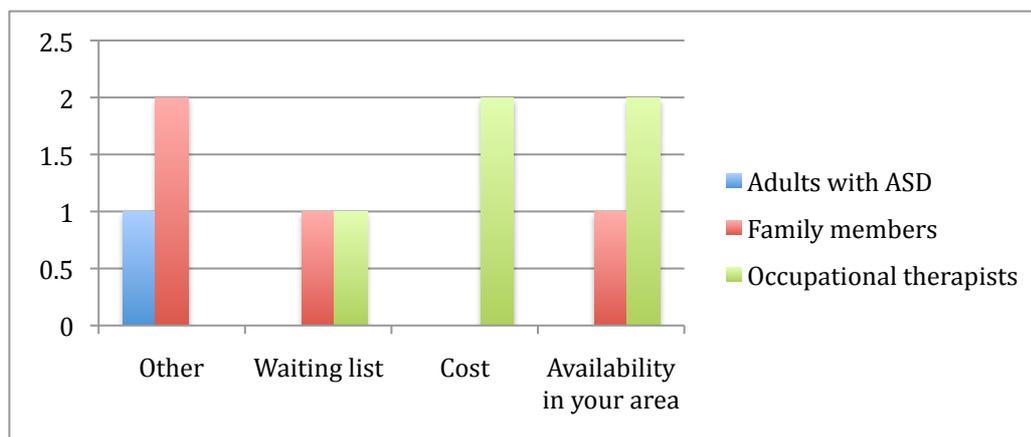


Figure 30: Nature of the difficulties

4.5.7. Possible improvements

Respondents thought that the collaboration with the families and the other professionals, as well as the quality and the quantity of the intervention, and the access to occupational therapy services needed to be improved. They also mentioned the lack of support available for individuals with ASD (the person is probably here talking about a lack of support in general, and not especially in the field of occupational therapy), and a lack of information provided to the families about occupational therapy and how to access these services.

To have a service for ASD adults would be great but that is not something that is important, we are the discarded in society, unwanted, expensive and unpopular. Why would anyone spend money on a non-profit condition that is what I see (Adult with ASD).

No information from the school, neither the Asperger association nor the psychologist... I really had to search by myself... A minimum of contact with schools would be useful in order to avoid being systematically offered a speech and language therapist, a psychomotricity therapist, etc., who cannot help a lot. I have the impression that schools, including middle schools, are not well informed that your intervention domain exists (Family member).

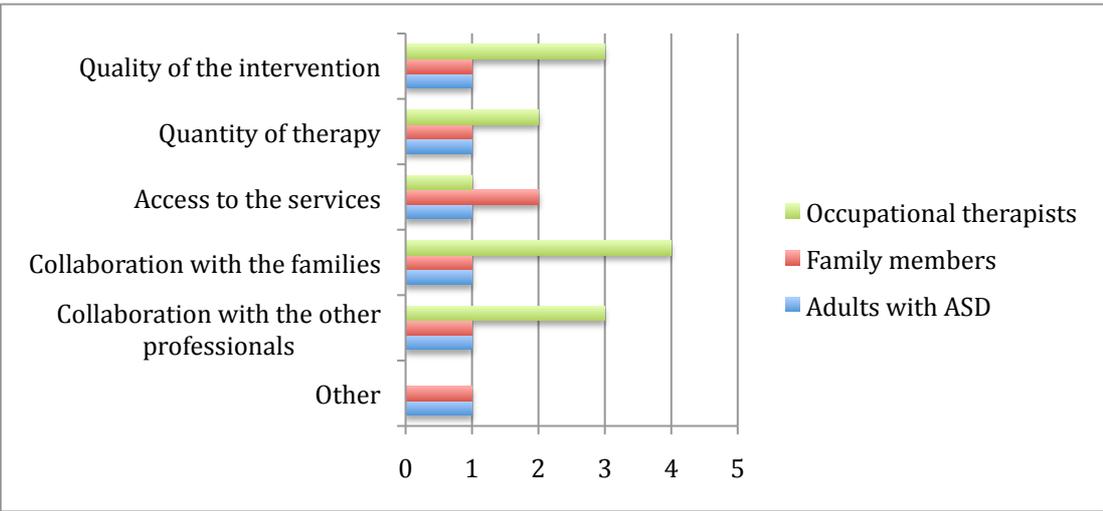


Figure 31: Propositions of improvements

4.5.9. Should occupational therapy be available as core services?

The ten respondents answering this question thought that occupational therapy should be available as core services for people with ASD. No one said it should not, nor that he did not know or had no opinion on that point.

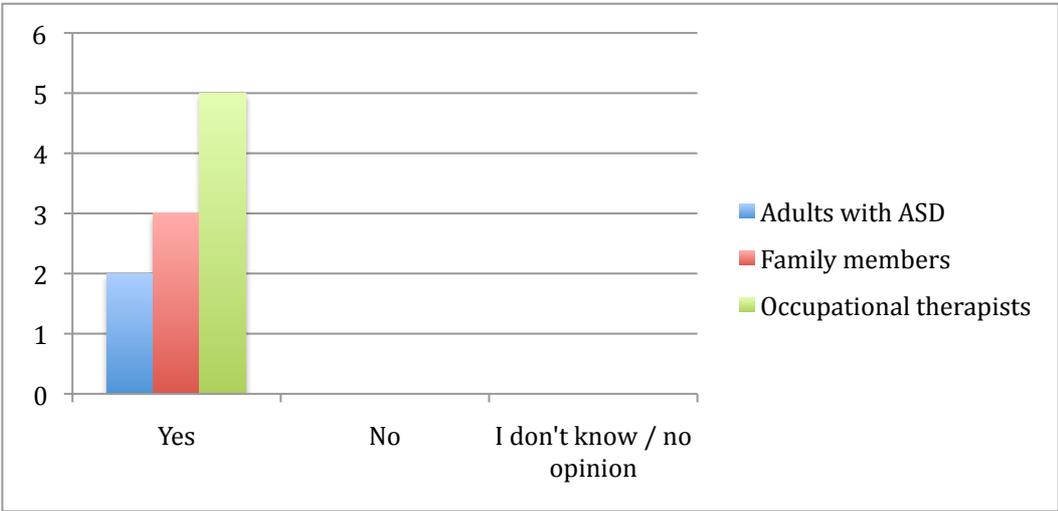


Figure 32: Should occupational therapy be available as core services?

CHAPTER 5: DISCUSSION

This research aimed to give an insight into the opinions of people with ASD, their family members, and occupational therapists exercising with individuals with ASD about the efficiency of occupational therapy services for people with autism. The results will be discussed in relation to the research questions: ‘Do service users and providers perceive occupational therapy as beneficial for individuals with ASD?’ and ‘Why do they think it is or not beneficial?’.

5.1. Do service users and providers think that occupational therapy is beneficial for individuals with ASD?

Both service users and providers seem to perceive occupational therapy as beneficial for people with ASD. Indeed, adults with ASD and family members whose relatives with autism had already had occupational therapy in the past or currently, and occupational therapists taking part in this research expressed their satisfaction with occupational therapy services, and they all considered it as useful for people with ASD. All of them also thought that it should be available as core services.

One family member had a less positive opinion than the other respondents. However, his child was the only preschool-aged child concerned at that point of the survey, and he had only received 2 hours of therapy so far. Perhaps it was too early to measure any evolution of his child and to feel that the occupational therapist had met his expectations. However, this person also rated the quality of the relationship and the collaboration between the occupational therapist and the child as quite bad. A good relationship with the patients is crucial in order to provide a good support, therefore that could be the reason why the intervention was not perceived as beneficial by this person. It could also be argued that occupational therapy is less useful for preschool children. However, as said before there was only one child of that age involved at that point of the study, therefore no generalisation can be made.

Family members whose relatives had never had occupational therapy also seemed to have a positive opinion of occupational therapy and seemed persuaded that it would be useful for their relatives with ASD. On the other hand, most of the adults with ASD who never had occupational therapy said they did not know whether occupational therapy could be helpful for them.

No significant correlation between the degree of satisfaction and the diagnosis of the person with ASD, the experience, the training, the context or the characteristics of the occupational therapy intervention could be made. Indeed, as seen in the literature the nature of the occupational therapy intervention can vary quite a lot. Case-Smith and Arbesman (2008) identified six types of interventions used in or of relevance of occupational therapy: sensory processing based interventions, relationship-based or interactive interventions, developmental skill-based programmes (e.g. the TEACCH), social-cognitive skills training, parent-mediated approaches, and intensive behavioural interventions (e.g. the ABA). Due to the number of different approaches and techniques employed by each occupational therapist involved in the study, it was therefore impossible to conclude which intervention resulted in better outcomes. Indeed, the respondents reported the use of skill-based interventions mainly (motor, cognitive and social skills, and self care), as well as environmental adaptations, play therapy, sensory integration intervention, intensive behavioural intervention, parent-mediated approach, touch-typing, the TEACCH, the PECS, and the 'Thérapie d'Échange et de Développement'. Sensory processing based approaches seem less common than expected: according to the literature, occupational therapists mainly use sensory based, and skills based interventions (Case-Smith & Arbesman, 2008; Watling, Deitz, Kanny & McLaughlin, 1999). However, that could be due to the fact that most respondents giving information about the nature of the intervention were from France, and it is probably less common for French occupational therapists to use this type of intervention. The therapy was also provided in a large variety of settings, and the place(s) of intervention could not be related to the degree of satisfaction and perceived usefulness either.

Moreover, many individuals with ASD receive other interventions at the same time as the occupational therapy. Some of them go to school, and/or benefit from speech and language therapy, the TEACCH, the ABA, the PECS, social skills groups, psychomotricity therapy, adapted sports, psychology, follow-up by a general practitioner (GP), genetician, neurologist, neuropsychologist, nurses, and educators, etc. It is therefore difficult to determine the extent in which occupational therapy and the other interventions contribute to the benefits observed for the person with ASD.

This research had a small sample size. Although the results indicated that service users and providers perceived occupational therapy as beneficial for people with ASD, it seems difficult to generalise these findings to the general ASD population.

5.2. Why do respondents think occupational therapy is beneficial or not for people with ASD?

5.2.1. Strengths of occupational therapy services

According to the respondents' observations, occupational therapy is useful for individuals with ASD, as it seems to improve not only their autonomy in activities of daily living, their motor skills, communication, social interaction, behaviour and activity; but also their executive functions, quality of life, sensory processing, touch-typing skills, and emotional well-being. Moreover, these progresses tend to be maintained after the intervention, although not always for a long time. These findings are consistent with the results obtained by Case-Smith and Arbesman (2008) regarding the outcomes of interventions used in or of relevance to occupational therapy with patients with autism. Moreover, occupational therapy services seem to satisfy service users and providers, and to meet partially or totally the expectations of patients with ASD and their families.

According to many participants, occupational therapy provides concrete solutions and environmental adaptations; it is adaptable, individualised, and progressive; based on evaluations; it allows to put the person in real situation of activity; aims to

produce valorising results and to increase the skills of people with ASD in diverse domains (e.g. motor skills, touch-typing, cognitive functions, etc), as well as their emotional well-being. Respondents also mentioned the following positive points about occupational therapy for individuals with ASD: the visual aspect of art therapy as a communication choice, listening, relay with the other professionals, facilitation of acceptance, and a regular stimulation.

The occupational therapists involved in this research use very diverse types of intervention. It is coherent as occupational therapy relies on a global view of the person, which enables these professionals to consider all the aspects of their patients, and to elaborate personalised and adapted programmes of intervention. Furthermore, individuals with ASD experience impairments in very diverse domains. The occupational therapists therefore need to use a variety of approaches to support these persons and help them with the diverse situations of disability they encounter in their daily life. Thus, it seems that their global approach of the person, as well as their professional skills, make occupational therapists very able to provide support to individuals with autism, to consider their variety of needs, and to employ diverse tools in order to achieve the objectives.

Moreover, all the ten participants answering the question ‘Do you think that occupational therapy should be available as core services?’ responded yes. Indeed, considering the apparent benefits of occupational therapy, and its capacity to meet the needs and expectations of people with ASD and their carers, this type of support should be offered to more individuals with autism.

5.2.2. Limits of occupational therapy and propositions of improvements

Only one family member of a person with ASD observed that occupational therapy helped with the sensory processing difficulties of his child. Two occupational therapists reported they used sensory integration assessments and techniques, but none of them seemed to measure any progress in the sensory integration of their patients, whereas they mentioned progresses in the autonomy in daily life activities,

communication and interaction, behaviour and activities, and quality of life. It could be argued that the sensory integration techniques they used contributed to the progresses in these areas, but as they both used a variety of interventions, it is impossible to know whether it was the sensory integration techniques or the other approaches employed that resulted in these progresses. Previous research studies indicated that sensory-based interventions (e.g. therapeutic touch, massage, brushing) were found to decrease tactile sensitivity, maladaptive behaviours, hyperactivity, stereotypic movements, and to increase attention (Case-Smith & Arbesman, 2008). However, according to Shaaf and Miller (2005), only half of the 80 studies investigating the outcomes of sensory integration therapy showed the efficiency of the treatment. Although sensory integrations techniques are commonly used by occupational therapists (Case-Smith & Arbesman, 2008), the evidence for their efficiency remains weak.

As seen before, most of the adults who never had occupational therapy did not seem to perceive occupation therapy as beneficial for people with ASD. However, they explained that they did not know whether it would be helpful for them, as they were not informed about occupational therapy and its role in the support of individuals with autism.

The results show that there is a lack of information about occupational therapy, its role in the support of people with ASD, and how to access occupational therapy services. People with autism and their carers should be better informed about the services they could access in order to have help with their difficulties. As occupational therapy seems to be beneficial for individuals with ASD, information should be provided about this profession and how it can help.

Half the service users participating in this survey had already had occupational therapy. However, individuals with ASD and relatives of persons with ASD who had already had occupational therapy were probably more likely to answer the questionnaire. In the general ASD population, probably less than 50% of the individuals have already accessed occupational therapy services.

Many people with ASD experience difficulties accessing occupational therapy services, for example for geographical reasons or because of the length of the waiting lists. Indeed, there is a lack of structures providing supports to individuals in certain geographical areas, and the waiting lists to see an occupational therapist can be very long. In the UK waiting lists are very unequal between the different counties, independently from the number of referral (Scottish Executive, 2003). To improve the accessibility to occupational therapy services, resources are needed to increase the number of occupational therapists, in accordance to the recommendations made by the PHIS Report (Public Health Institute of Scotland, 2001).

In order to limit waiting times and improve services for assessment and diagnosis of children and adults, resources are required to train and employ more specialist professionals in all agencies (Public Health Institute of Scotland, 2001, p.5).

There also seems to be a lack of service provision for adults with ASD, especially for those who are diagnosed with Asperger Syndrome or high-functioning autism. It is perhaps because many of them are diagnosed very late, or because it is assumed they do not need help as they are at the more able end of the spectrum. However, many of them do need support, and occupational therapy may help them with all the difficulties they encounter in their daily life.

French respondents also evoked financial reasons. Indeed, in France occupational therapy is refunded by the national insurance service when provided in the context of an institution, hospital, clinic, etc., but not in the context of an independent practice.

The collaboration with the families and the other professionals also need to be improved. Although a majority of respondents rated it as good or very good, it is not always the case. Moreover, one adult with ASD reported he would have liked to receive more information and explanation about the assessments and the objectives of the intervention. The British Association and College of occupational therapists

code of conduct (College of Occupational Therapists, 2010), the Health and Care Professions Council (HCPC) Standards of Proficiency (Health and Care Professions Council, 2012), and the HCPC Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2007) underline the importance of providing information to the patients in order for them to give their informed consent, as well as the importance of the partnership with the carers and other professionals.

You must always provide adequate information to a service user in order for them to provide informed consent (College of Occupational Therapists, 2010, p.7).

You should work in partnership with the service user and their carer(s), throughout the care process, respecting their choices and wishes and acting in the service user's best interests at all times (College of Occupational Therapists, 2010, p.16).

French occupational therapists expressed the need for more recognition of the profession and its role in the support of individuals with ASD. Indeed, according to the researcher's experience, occupational therapy is a relatively recent and unknown profession in France (the first diplomas of occupational therapist were delivered in the 1970s). As occupational therapy seems to be useful for people with ASD, it seems indeed essential to make its role be better recognised, and to address persons with ASD who may benefit from it to these services.

A family member and several occupational therapists urged the need of a better training in the functioning of individuals with ASD, as well as more specific assessment tools and interventions. According to the results of the survey and to the author's experience, occupational therapists working with people with ASD do not use a lot of assessment tools that are specific to ASD and/or to occupational therapy. It would be useful to develop evaluations that would be more adapted to the practice of occupational therapy with patients with ASD, in order to better assess and meet their needs.

As mentioned by an adult with Asperger syndrome participating in the research, the context of the intervention is very important, and support should be provided on a one-to-one basis or in small groups, and people with ASD should not be included in a group of people with diverse mental and behavioural issues that may represent a source of fear and stress for the person with autism.

5.3. Limits of the study

According to Odom et al. (2003), research into the effectiveness of interventions for individuals with ASD has to employ an experimental design.

To determine the effectiveness of intervention or educational practices for young children with autism, the causal question of whether an intervention has an effect is the most relevant. To address this question, researchers must use an experimental design to tightly control for extraneous variables that might account for changes that occur in the dependent or outcome variables for children when an intervention or teaching approach is applied (Odom et al., 2003, p.167).

However, according to Foster and Mash (1999), the statistical measure of the outcomes does not mean that a meaningful change happened for the client and their relatives. Subjective evaluations by the clients, their families or significant others, or by experts or representative judges allow to give an insight in their experience and opinion of the intervention, and to show whether the intervention has made a significant difference in the person's quality of life.

The online nature of the survey made impossible to check whether the participants were really meeting the inclusion criteria. However, it was assumed that people who do not meet these criteria would not choose to answer the questionnaires, and the only way to access the survey was to have the address of the website, which was

only advertised in websites and communities related to autism or occupational therapy.

The time constraints were a limit for this research, as the data were gathered during one month only. A longer period of publication would probably have been useful in order to collect more information. Moreover, as participants were free to jump the questions they did not want to answer, many of them jumped several questions. Although a total of 27 respondents were counted, only a few people filled in the whole survey. It results in a small sample size for the study, therefore it is difficult to statistically analyse the data, and to generalise the findings to the general ASD population.

The numbers of participants in each group (adults with ASD / family members / occupational therapists), and from each country (UK / France) were very unequal. Cultural differences conditioning the occupational therapy interventions were expected and made the data analysis more difficult to conduct.

CONCLUSION

This survey-based research aimed to determine whether adults with ASD, their family members, and occupational therapists perceived occupational therapy as beneficial for people with ASD.

The results indicated that occupational therapy may be beneficial for people with ASD. Occupational therapy has the skills to help these individuals with their very diverse difficulties and to facilitate their autonomy in their meaningful activities. However, some improvements need to be done to ameliorate these services, and further research is still needed in order to increase the evidence base for occupational therapy, and to better respond to the needs and expectations of patients with ASD and their carers. A better provision of services, as well as more communication about the role of occupational therapy in the support of people with autism would improve the access to these services. A better training in the functioning of people with ASD, as well as the development of specific evaluations tools, more specific interventions, and a better collaborative practice would allow to ameliorate the quality of the support provided.

Further research is needed in order to evidence whether occupational therapy is beneficial for people with ASD, and what are the benefits of each type of approach. Most of the previous studies focused on sensory integration techniques, which constitute only one of the approaches used with people with autism. Considering the large diversity of occupational therapy interventions, it would be interesting and useful to study separately the outcomes of the different methods and techniques employed in future research. This would contribute to the evidence-based practice of occupational therapy for individuals with ASD.

APPENDIX 1: Questionnaire for adults with ASD

PART 1

Information about you

1. How old are you?

2. What is your diagnosis?

- Classic autism
- Asperger Syndrome
- High Functioning Autism
- Other (please specify)

3. Do you have any co-occurring condition?

- Yes
- No

If yes, please specify

4. Have you had occupational therapy (in the past or currently)?

- Yes
- No

PART 2

Please fill in this part of the questionnaire only if you have never had occupational therapy. If you have already had occupational therapy, please do not answer these questions and click on the "next" button at the bottom of this page to jump directly to the next page.

5. If you have never had occupational therapy, please explain why.

- No need for it
- Did not know about OT services
- Difficulty to access OT services
- I don't know
- Other (please specify)

6. Would you have liked to have occupational therapy?

- Yes
- No
- I don't know / no opinion

7. Could you explain why you would have liked or not to have had occupational therapy?

8. Please use this space to add anything you would like to add, to specify, or to make any comment on this questionnaire.

PART 3

Please fill in this part of the questionnaire only if you have already had occupational therapy in the past or currently.

If you have never had occupational therapy, please do not answer these questions and click directly on the "next" button at the bottom of this page.

9. When did / do you have occupational therapy?

(If you have had occupational therapy at several periods of your life, please separate your answers by commas)

Your approximate age
at the time of the
intervention (Pre-
school age child,
school age child,
adolescent, or adult)

Approximate duration
of the therapy

Approximate
frequency of the
sessions (e.g. every 2
weeks, weekly, twice
a week, etc.)

Approximate length of
each session (e.g. 30
minutes, 1 hour, etc.)

10. Did / Do you see an occupational therapist (OT) only for an assessment, or for an intervention?

- Assessment only
- Assessment plus intervention
- I don't know

11. What was/is the nature of the intervention provided by the OT? (Tick all that apply)

- Sensory integration
- Motor skills
- Autonomy in daily life activities
- Environmental adaptations
- Social skills
- Cognitive skills / executive functions
- Play therapy
- Intensive behavioural intervention
- Parent-directed / parent-mediated approach
- I don't know
- Other (please specify)

12. Where did/does the OT intervention take place? (Tick all that apply)

- Home
- School
- Hospital
- Clinic
- Institution
- Independent practice
- Your workplace
- I don't know
- Other (please specify)

13. Did you attend a school at the time of the OT intervention?

- Yes
- No

**14. If yes, please indicate what kind of school and class you attended.
(Tick all that apply)**

	A "typical" class	A class for children with various learning difficulties	A class for children with Pervasive Development Disorders (PDD)	A class for children with ASD	I don't know
In a mainstream school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In a school for children with special needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify)

15. Was/Is any of these other interventions provided to you (at the time of the OT intervention)? (Tick all that apply)

- Speech and language therapy
- TEACCH (Treatment and Education of Autistic and related Communication handicapped Children)
- ABA (Applied Behaviour Analysis)
- PECS (Picture Exchange Communication System)
- I don't know
- Other (please specify)

16. Did/does your OT work in collaboration with the other professionals involved in your support?

- A lot
- Quite a lot
- A little bit
- Not at all
- I don't know

17. Is/was your experience of occupational therapy services overall positive?

- Very positive
- Quite positive
- Neutral
- Quite negative
- Very negative

18. Is/was occupational therapy useful for you?

- Very useful
- Quite useful
- A little bit useful
- Not at all
- I don't know

19. What areas did/do you progress in (during the OT intervention)? (Tick all that apply)

- Sensory processing
- Motor skills
- Autonomy in daily life activities (e.g. dressing, bathing/showering, feeding)
- Communication and social interaction
- Behaviour and activity
- Executive functions
- Quality of life
- I don't know
- Other (please specify)

20. If you noticed any progress, was it maintained after the intervention?

- Yes, definitively
- Yes, for a long time
- Yes, but only for a short time
- No
- I don't know (tick this box if the OT intervention is not finished or has finished very recently)

21. Did the occupational therapist meet your expectations?

- Mostly
- To quite a large extent
- A little bit
- Not at all
- I don't know

22. How would you rate the quality of the relationship and the collaboration between the OT and you?

- Very good
- Quite good
- Neutral
- Quite bad
- Very bad
- I don't know

23. How would you rate the quality of the relationship and the collaboration between the OT and your family?

- Very good
- Quite good
- Neutral
- Quite bad
- Very bad
- I don't know / Not applicable

24. How would you rate the quality of the relationship and the collaboration between the OT and the other professionals?

- Very good
- Quite good
- Neutral
- Quite bad
- Very bad
- I don't know / Not applicable

25. Can you mention up to 3 things you find particularly good about OT for individuals with ASD?

26. Can you mention up to 3 things you would like to change about OT for individuals with ASD?

27. Did you have difficulties accessing OT services?

- Yes
- No

28. If yes, please explain the reason.

- Availability of OT services in your area
- Cost of OT services
- Waiting list
- Other (please specify)

29. Do you think the occupational therapy service you received/receive can be improved in terms of: (Tick all that apply)

- Quality of the intervention
- Quantity: frequency/length of the sessions
- Access to the services
- Collaboration with the family
- Collaboration with other professionals
- Other (please specify)

30. Do you think that occupational therapy should be available as core services?

- Yes No I don't know / no opinion

31. Please use this space to add anything you would like to add, to specify, or to make any comment on this questionnaire.

Thank you for your participation in this research.
You can now click on the "done" button if you wish to submit your answer.

APPENDIX 2: Questionnaire for family members of individuals with ASD

PART 1

Information about your relative with Autism Spectrum Disorder (ASD)

1. What is your relationship to the individual with ASD?

- Parent Sibling Grandparent
 Other (please specify)

2. How old is your relative with ASD?

3. What is his/her diagnosis?

- Classic autism
 Asperger Syndrome
 High Functioning Autism
 Other (please specify)

4. Does he/she have any co-occurring condition?

- Yes No

If yes, please specify

5. Has your relative with ASD had occupational therapy (in the past or currently)?

- Yes No

PART 2

Please fill in this part of the questionnaire only if your relative with ASD has never had occupational therapy.

If your relative with ASD has already had occupational therapy, please do not answer these questions and jump directly to the 3rd of the questionnaire by clicking on the "next" button at the bottom of this page.

6. If your relative with ASD has never had occupational therapy, please explain why.

- No need for it
 Did not know about OT services
 Difficulty to access OT services
 I don't know
 Other (please specify)

7. Would you have liked your relative to have had occupational therapy?

- Yes
- No
- I don't know / no opinion

8. Could you explain why?

9. Please use this space to add anything you would like to add, to specify, or to make any comment on this questionnaire.

PART 3

Please fill in this part of the questionnaire only if your relative with ASD has already had occupational therapy in the past or currently.
If your relative has never had occupational therapy, please do not answer these questions and click on the "next" button at the bottom of this page.

**10. When did/does your relative with ASD have occupational therapy?
(If your relative has had occupational therapy at several periods of his/her life, please separate your answers by commas)**

Approximate age of your relative at the time of the intervention (Pre-school age child, school age child, adolescent, or adult)

Approximate duration of the therapy

Approximate frequency of the sessions (e.g. every 2 weeks, weekly, twice a week, etc.)

Approximate length of each session (e.g. 30 minutes, 1 hour, etc.)

11. Did/Does your relative with ASD see an occupational therapist (OT) only for an assessment, or did he receive an intervention?

- Assessment only
- Assessment plus intervention
- I don't know

12. What was/is the nature of the intervention provided by the OT? (Tick all that apply)

- Sensory integration
- Motor skills
- Autonomy in daily life activities
- Environmental adaptations
- Social skills
- Cognitive skills / executive functions
- Play therapy
- Intensive behavioural intervention
- Parent-directed / parent-mediated approach
- I don't know
- Other (please specify)

13. Where did/does the OT intervention take place? (Tick all that apply)

- Home
- School
- Hospital
- Clinic
- Institution
- Independent practice
- Workplace of the individual with ASC
- I don't know
- Other (please specify)

14. Does/did your relative with ASD attend a school at the time of the OT intervention?

- Yes
- No

15. If yes, please indicate what kind of school and class he/she attended/attends. (Tick all that apply)

	A "typical" class	A class for children with various learning difficulties	A class for children with Pervasive Development Disorders (PDD)	A class for children with ASD	I don't know
In a mainstream school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In a school for children with special needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. Was/Is any of these other interventions provided to your relative with ASD at the time of the OT intervention? (Tick all that apply)

- Speech and language therapy
- TEACCH
- ABA
- PECS
- I don't know
- Other (please specify)

17. Did/does your OT work in collaboration with the other professionals involved in the support of your relative with ASD?

- A lot
- Quite a lot
- A little bit
- Not at all
- I don't know

18. Is/was your experience of occupational therapy services overall positive?

- Very positive
- Quite positive
- Neutral
- Quite negative
- Very negative

19. Is/was occupational therapy useful for your relative with ASD?

- Very useful
- Quite useful
- A little bit useful
- Not at all
- I don't know

20. What areas your relative with ASD progressed in? (Tick all that apply)

- Sensory processing
- Motor skills
- Autonomy in daily life activities (e.g. dressing, bathing/showering, feeding)
- Communication and social interaction
- Behaviour and activity
- Executive functions
- Quality of life
- I don't know
- Other (please specify)

21. If you noticed any progress, was it maintained after the intervention?

- Yes, definitively
- Yes, for a long time
- Yes, but only for a short time
- No
- I don't know (tick this box if the OT intervention is not finished or has finished very recently)

22. Did the occupational therapist meet your expectations?

- Mostly
- To quite a large extent
- A little bit
- Not at all
- I don't know

23. How would you rate the quality of the relationship and the collaboration between the OT and the individual with ASD?

- Very good
- Quite good
- Neutral
- Quite bad
- Very bad
- I don't know

24. How would you rate the quality of the relationship and the collaboration between the OT and your family?

- Very good
- Quite good
- Neutral
- Quite bad
- Very bad
- I don't know

25. How would you rate the quality of the relationship and the collaboration between the OT and the other professionals?

- Very good
- Quite good
- Neutral
- Quite bad
- Very bad
- I don't know
- Not applicable

26. Can you mention up to 3 things you find particularly good about OT for individuals with ASD?

27. Can you mention up to 3 things you would like to change about OT for individuals with ASD?

28. Did you have difficulties accessing OT services?

- Yes
- No

29. If yes, please explain the reason.

- Availability of OT services in your area
- Cost of OT services
- Waiting list
- Other (please specify)

30. Do you think the occupational therapy service your relative received/receives can be improved in terms of: (Tick all that apply)

- Quality of the intervention
- Quantity: frequency/length of the sessions
- Access to the services
- Collaboration with the family
- Collaboration with other professionals

Other (please specify)

31. Do you think that occupational therapy should be available as core services?

- Yes No I don't know / no opinion

32. Please use this space to add anything you would like to add, to specify, or to make any comment on this questionnaire.



Thank you for your participation in this research.
You can now click on the "done" button if you wish to submit your answer.

APPENDIX 3: Questionnaire for occupational therapists

PART 1

Information about your training, your professional experience, and your work.

1. Could you please list the courses (initial or continuing training) you undertook that are relevant to your practice of occupational therapy with individuals with Autism Spectrum Disorders (ASD)?

2. How long is your experience of working with individuals with ASD?

3. Do you work full time?

- Yes
- No (please specify the rate)

4. Could you please give an estimation of the percentage of your patients who have an ASD (for example 100% if you only work with individuals with ASD)?

- 100%
- 80-100%
- 50-80%
- Less than 50%

5. Which sector do you work in?

- Health and Social Care sector (NHS)
- Private health care
- Charitable organisations
- Independent practice
- Other (please specify)

PART 2

Information about your intervention with individuals with ASD

6. How old are the individuals with ASD you have worked with? (Tick all that apply)

- Pre-school children
- School age children
- Adolescents
- Adults

7. What are their diagnoses? (Tick all that apply)

- Classic autism
- Asperger syndrome
- High functioning autism
- Other (please specify)

8. Do they have co-occurring conditions?

- No
- Yes (please specify)

9. How long does the therapy usually last?

Minimal duration

Maximal duration

Average duration

10. What are the usual frequency and length of the sessions?

Frequency

Length

11. What kind of assessment do you practice? (Tick all that apply)

- Sensory processing
- Motor skills
- Autonomy in the activities of daily living
- Autonomy in instrumental activities
- Environment (e.g. home, school, work)
- Other (please specify)

12. Do you use standardised assessments?

- A lot
- Quite a lot
- A little
- Not at all
- I don't know

13. What is the nature of the intervention you provide? (Tick all that apply)

- Sensory integration
- Motor skills
- Autonomy in daily life activities
- Environmental adaptations
- Social skills
- Cognitive skills / executive functions
- Play therapy
- Intensive behavioural intervention
- Parent-directed / parent-mediated approach
- Other (please specify)

14. Where does your intervention take place? (Tick all that apply)

- Home
- School
- Hospital
- Clinic
- Institution
- Independent practice
- Workplace of the individual with ASC
- Other (please specify)

15. If you work with children with ASD, how many of them attend a school (at the time of the OT intervention)?

- 80-100%
- 60-80%
- 40-60%
- 20-40%
- 0-20%
- I don't know

16. What kind of school(s) and class(es) do most of them attend? (Tick all that apply)

	A "typical" class	A class for children with various learning difficulties	A class for children with Pervasive Development Disorders (PDD)	A class for children with ASC	I don't know
In a mainstream school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In a school for children with special needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. What kind of other interventions are often provided to the individuals with ASD you work with (at the same time as your intervention)? (Tick all that apply)

- Speech and language therapy
- TEACCH
- ABA
- PECS
- I don't know
- Other (please specify)

18. Do you work in collaboration with the other professionals involved in the support of the individuals with ASD you work with?

- A lot
- Quite a lot
- A little bit
- Not at all

19. Do you work in collaboration with the families of the individuals with ASD you work with?

- A lot
- Quite a lot
- A little bit
- Not at all

PART 3

Your opinion about your intervention with individuals with ASD

20. Is your opinion of the support you provide to individuals with ASD overall positive (in terms of the quality of your intervention)?

- Very positive
- Quite positive
- Neutral
- Quite negative
- Very negative

21. Do you think that your intervention is useful for the individuals with ASD you work with?

- Very useful
- Quite useful
- A little bit useful
- Not at all
- I don't know

22. What areas do your patients with ASD usually progress in? (Tick all that apply)

- Sensory processing
- Motor skills
- Autonomy in daily life activities (e.g. dressing, bathing/showering, feeding)
- Communication and social interaction
- Behaviour and activity
- Executive functions
- Quality of life
- I don't know
- Other (please specify)

23. If you noticed any progress, was it maintained after the intervention?

- Yes, definitively
- Yes, for a long time
- Yes, but only for a short time
- No
- I don't know (tick this box if the OT intervention is not finished or has finished very recently)

24. Do you think that you usually meet your clients' and/or their families' expectations?

- Mostly
- To quite a large extent
- A little bit
- Not at all
- I don't know

25. How would you rate the quality of the relationship and the collaboration between the individual with ASD and you?

- Very good
- Quite good
- Neutral
- Quite bad
- Very bad
- I don't know

26. How would you rate the quality of the relationship and the collaboration between the families of the individuals with ASD and you?

- Very good
- Quite good
- Neutral
- Quite bad
- Very bad
- I don't know

27. How would you rate the quality of the relationship and the collaboration between the other professionals and you?

- Very good
- Quite good
- Neutral
- Quite bad
- Very bad
- I don't know
- Not applicable

28. Can you mention up to 3 things you find particularly good about OT for individuals with ASD?

29. Can you mention up to 3 things you would like to change about OT for individuals with ASD?

30. Did the people with ASD you work with have difficulties accessing OT services?

- Yes
- No
- I don't know

31. If yes, please explain the reason.

- Availability of OT services in your area
- Cost of OT services
- Waiting list
- Other (please specify)

32. Do you think your intervention can be improved in terms of: (Tick all that apply)

- Quality of the intervention
- Quantity: frequency/length of the sessions
- Access to the services
- Collaboration with the family
- Collaboration with other professionals
- Other (please specify)

33. Do you think that occupational therapy should be available as core services?

- Yes
- No
- I don't know / no opinion

34. Please use this space to add anything you would like to add, to specify, or to make any comment on this questionnaire.

Thank you for your participation in this study.
You can now click on the "done" button if you wish to submit your answer.

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Association Nationale des Ergothérapeutes Francophones (ANFE) (national association of French-speaking occupational therapists): <http://www.anfe.fr>

British Association of Occupational Therapists and College of Occupational Therapists: <http://www.cot.org>

Website of Delphine Dechambre: <http://delphinedechambre.fr/>

Weblog 'L'ergothérapie à La Main Tendue': <http://lamaintendue.blog4ever.com>

National Autistic Society: <http://www.autism.org.uk>

National Health Service: <http://www.nhs.uk>

Scotland Autism Network: <http://www.scottishautism.org/>

Talk About Autism: <http://www.talkaboutautism.org.uk/>