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An examination of the quality of and access to individually tailored services for adults with autism in Irish society

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Abstract:

The purpose of this paper is to outline the research carried out in relation to autistic adults needs within Irish society. The paper examines briefly the nature and characteristics of autism and identifies the lack of support services available to autistic adults. It investigates the transitioning of an adolescent with ASD from child-provided services to adult-specialised services. An identification of the core needs and service provisions required for adults with autism is investigated. An exploration of the extent to which full inclusion is promoted in services for adults with autism is also outlined. The importance of advocacy groups in campaigning for the needs of autistic adults is examined. The paper examines the development and identification of services for ASD adults in recent years. The research findings present autistic adults as an underrepresented group both in literature and Irish policy. The exclusion of autistic adults in Ireland is unacceptable and needs to be highlighted continuously until service provision is adequate to meet the needs of all autistic adults.

Keywords: Autism; transitioning; social inclusion; support services; advocacy groups.

Introduction

Autism cannot be defined simply as there are a range of disabilities on the autistic spectrum. Autistic Spectrum Disorders (ASD) include three main disorders including the autistic disorder, Asperger's Syndrome and Pervasive Developmental Disorder. To examine and identify specialised services for autistic adults one must gain an understanding of the nature of autism.

Autism can be identified by a range of cognitive and behavioural impairments. Most children with autism are not diagnosed with autism until they are three years of age as the signs become apparent, as it is at this age that children tend to develop social and motor skills. Small signs may appear before this age such as the absence of a social smile. Autistic children also avoid making any eye contact at an early age. Dodd (2005) argues that because autistic people lack social skills, interaction with others is difficult as, for instance, they do not possess good communication skills. They are often withdrawn, have poor eye contact and shun social contact. For this reason they may seem odd or aloof to other people. Autistic people often appear to be cut-off from the rest of the world due to their inability to interact with others. Those suffering with autism often have an inability to empathise with others. This lack of empathy is caused by the fact that they do not sense or understand the feelings and emotions of others.

In general terms people with ASD lack the understanding of the unwritten rules of the social world, for example turn taking which is considered vital as it is used in conversation, games and driving. Their lack of vocabulary can impair them to communicate well with others as they may not possess verbal communication skills. In addition to verbal communication, non-verbal communication can cause problems for people with ASD also. People with ASD are often unable to interpret body language such as raised eyebrows for the look of confusion. People with ASD may develop behavioural problems as a result of their condition and the cultural/social perceptions interpretations of the symptoms outlined above. It is considered necessary for them to be in an original structural environment as this allows them to have

predictability and routine in an environment they are familiar with. People with ASD are thought to enjoy routine because it offers predictability. They may become very agitated if a routine they are used to is altered in some way, and this may in some cases result in behavioural situations. Autistic people often develop a special interest in certain objects and become fascinated and obsessed with this object. Individuals with ASD's may suffer abnormalities in their sensory perceptions and this may cause behaviours, for example they can have an extreme sensory sensitivity to rough clothing and have a strong reaction to taste.

Dodd (2005) suggests that in order to understand the disorder and to develop adequate services to meet the needs of autistic adults we must firstly understand their thinking and styles of learning. Autistic individuals present difficulties in focusing and maintaining their attention, they obtain and process information in a unique way, therefore visual presentation of information acts as an effective way of learning for autistic people. Dawson and Frith (1989) emphasise the importance of Kanner's (1943) original description of the characteristics of autism, such as the inability to establish social relatedness and the failure to communicate purposefully as important elements for further research. Kanner's original understanding of autism is still recognised as the focal points for diagnosing and understanding autism in society. Debates around autism often tend to focus on services for children, rarely including adults. This issue can be highlighted in many pieces of legislation where autistic adults are often excluded in provisions for the future. The Education for Persons with Special Needs Act (EPSN) 2004 focuses on the education of children under the age of 18 however as the child approaches adulthood the child's Education Plan must take into consideration the provisions which may need to be made to continue the child's education or training in adulthood. This Act includes the provision of services for children who are suffering with autism as they enter adulthood. Policies such as this are crucial in identifying autistic adults with special needs in society. Autism may occur in isolation or may be presented with other conditions in an autistic individual such as intellectual impairment, Down's syndrome, attention deficit hyperactivity disorder, cerebral palsy and epilepsy. One in four children with ASD develops

seizures as stated by Children with Autism: A Parent's Guide (2000). Seizures develop in ASD individuals during childhood or adolescence. These seizures are caused by abnormal electrical activity in the brain which cause temporary loss of consciousness, a body convulsion, unusual movements or staring spells. In summary, autism is a complex developmental disability. Autism is a spectrum disorder and it affects each individual differently and to varying degrees. Autism knows no racial, ethnic, social boundaries, family income, lifestyle or educational levels and can affect any family, and any child. The prevalence of autism is four times more prevalent in boys than in girls.

Fieldwork Research

The fieldwork research is composed of qualitative research using semi-structured interviews. The interviewees consisted of four service providers who work with autistic adults in society. The interview participants include a psychologist, a care assistant, a TEACCH instructor and a senior staff nurse. The TEACCH programme aims to develop communication skills and to help individuals work and play independently of adults. The research is focused on service providers' views. The interview schedule contains core themes such as transitioning, core needs and service provision, advocacy groups, identification of the main developments in the area and also full inclusion of adults with ASD's. The research investigated how the needs of adults with autism in Ireland have been met by service providers and also examines how service providers predict service provision to evolve in recent years. Due to the limited literature on autistic adults in society the role of fieldwork research is essential in my collection of data on the research area.

Transitioning of Young Adults into Society

The theme of transitioning of adolescence and young adults with autism in Irish society has become one of the focus points of my research. The theme involves the transfer of adolescence with autism from child provided services to adult services. This transitioning period has major implications on the future life of the individual with autism. This theme has featured in policy as early as the 1994 *Green Paper*

Services for Persons with Autism. Throughout the *Report on the Task Force on Autism* (2001) this theme features in many submissions to the report. The interviewees were asked if the service they provide integrates this transitioning period into the life of the adults for whom they provide services. The majority of the interviewees stated that the service users they work with were not involved in any transitioning when they became young adolescence. Participant B indicated that transitioning depended on staffing and whether staff were willing or able, to assist the autistic individual in the transitioning period. Participant B also felt that for transitioning to take place it was vital that there was good communication and liaising between the child provided services and adult services for people with ASD's. The failure to transition service users from one service to another is echoed by participants C and D who identified service users who were provided with a service as children but as soon as individuals reached the transitioning age no service was put in place for them. One participant held opposing views to the other participants involved in the interviews. Participant A identified how the service he provides deals specifically with transitioning adolescence and young adults through various services such as respite, residential and day service supports. He states "*We deal with transitioning, that's what we do*". This service provider outlines how the service he works in estimates the number of individuals who will need to be transitioned in coming years. The examination of the intellectual disability and autism database is one of the first steps they take in identifying the percentage of people with autism who require transitioning. He also illustrates how transitioning is integrated into the lives of those for whom they provide services. This participant's comments suggest that he viewed transitioning as focal point in the service which he provides for autistic adults. However, the general view was that transitioning was not practised amongst individuals who were transferring from child-provided services to adult services for individuals with autism. However, the opposing view of Participant A suggests that transitioning for some individuals with autism does actually take place within certain services for autistic adults. When participants were asked about the state's adequacy in providing service provision during this transitional period for autistic adults the general view of all participants was that sufficient funding is not allocated by the state to support transitioning

services. Participant A gives a detailed breakdown of how funding is allocated between organisations. This inadequacy in funding is mirrored in this general view “Unfortunately the amount of money that’s available will only cover 20-25% of what organisations are looking for. People then stay on waiting lists.” Participant D identifies how service users are expected to pay for specialised equipment and development and learning tools that are not provided by the state. It was the opinion of participant B that the State were not willing to invest in autistic individuals because they would never see a return on the money they invested in them. In the context of the general concern with poor state adequacy in supporting transitional services for autistic adults all participants held the view that the state were not providing realistic funding to implement transitioning services for autistic adults. As a result of this inadequacy, waiting lists have emerged and behaviours have escalated amongst autistic adults due to inconsistency in routine therefore restricting their ability to live their lives to their best potential.

Identification of Core Needs and Service Provision

To identify the service needs of autistic adults participants were asked what they considered to be the core needs of adults with autism in society. A variety of replies were offered. Participants mentioned various needs which to them were vital in supporting the autistic adult. The need of individual treatment was identified by participant A. The views of participant B were more focused on the need to maintain stability in the life of autistic adults. S/he was of the opinion that adjustment in the life of the ASD adult should be promoted slowly and transition from services explained to service users. The views expressed by participant C differed again in the identification of core needs for adults with autism in Irish society. This interviewee stated that education was the core need along with integration. By activating education in the life of individuals with ASD this participant saw the opportunity for high functioning autistic adults to gain employment and so integrate better into society. The core need to experience integration was shared by participant D also who expressed their view of the core need of adults with autism as “*integration. Probably the biggest one, I know the majority of adults with autism depending on the range of their disability can*

actually integrate with others to a degree". This participant felt that integration should occur on an educational basis beginning within day care and pre-schools following on to primary education right up to education within training centres and activation skills for autistic adults. The theme of equality appears to feature in all the core needs stated by the participants as all service providers mention needs that are vital in contributing to the quality of life of all adults with autism in Irish society. When participants were asked how these core needs were met similar views were shared in meeting these needs. All participants identified staff as being essential in meeting the core needs of autistic adults. This general view is expressed by participant D; *"The needs are mainly met by the staff and the multi-disciplinary team such as the occupational therapist, speech and language therapist, physiotherapist and psychiatrist"*. The view that person-centred planning and care along with tailoring the service around the individual, and not vice versa, was offered by participant A. This interviewee also stated that individualised packages of care and measuring the progress of staff and the organisation are essential in providing adults with autism with a better quality of life. Participant A suggests that service users' progress in life is a credit to the staff and support who are involved in caring for those with ASD's. The need of adequate staffing is voiced by all participants in meeting the needs of individuals with ASD's. However, different organisations organise their staff in various services so as to meet the core needs of the autistic adult population. The arrangement and organisation of staff working with adults with autism is mainly dependent on the level of autism that is present in individual service users. As expressed by participant C, just because you are labelled autistic doesn't necessarily mean you have entirely the same needs as others with autism. Individuals with autism have different needs. Therefore, as identified by participant A, the service must be tailored around the individual and not the other way around.

Importance of Advocacy Groups

The development of advocacy groups has grown significantly within society. Participants were asked to express their views on how important they consider advocacy groups to be in campaigning for the needs of autistic adults. Opinions

offered here were quite interesting, as similar feelings were shared by all participants. All interviewees identified their restriction as an organisation in advocating on behalf of the service users they work with and also outlined the necessity of those with autism having an advocate to voice their needs. Participant D mirrors the general views shared by all four participants in this quote; *“Not even an advocacy group but an advocate. Nurses can do so much but we are restricted by our professional role and our employer, so we are caught in that way. An independent advocate or an advocacy group could do a lot more”*. The need for an advocate for those who cannot advocate for themselves is expressed by participant A. The views offered by participant B illustrates how advocacy groups have the ability to gain more media attention than organisations. *“When an external group is very public in advocating and pushing the government to do more it’s very vocal and gets more media attention for example Kathy Sinnott. Also groups and organisations are bound to confidentiality we can’t shout from the roof-tops”*. Opinions offered by participant C were very concrete. Participant C also reflected the views similar to participant B identifying the parents of children who act as an advocate campaigning for service provision to meet the needs of their autistic child. The views offered by this participant relate how advocacy is essential particularly in the area of autistic adults in Irish society where *“service provision for autistic adults does not exist and they need someone to voice their needs”*. The role of, not just advocacy groups but, an advocate for individuals with autism was identified as essential by all interview participants. The general concern was that all individuals with autism in Irish society are represented by others, as due to their disability they are unable to fully voice their own needs and articulate the level of inequality they experience in their everyday lives.

Development and Implementation of Services in Recent Years

Within the last decade the identification of individuals with autism has featured in literature, policy and legislation. Participants were asked to comment on what they considered to be the main developments in the last 10 years in relation to the needs of autistic adults. Views varied significantly here as to what were the main developments

that occurred. In general participants highlighted the identification of adults with autism in society. Participants did not share similar views in this area. The development in policy featured as a major turning point for participant A. The publication of the 2004 *Education for Persons with Special Educational Needs Act* (EPSEN) and the 2005 *Disability Act* were identified by this interviewee. The mainstreaming of individuals with autism into society as opposed to segregating individuals with autism into special schools was highlighted. Participant D identifies the reduction in stigma that was once attached to individuals with intellectual disabilities. The role of institutions and the ‘hiding away’ of those with intellectual disabilities and autism was also expressed by participant C. “*A lot of people in the past would have been sent away and their behaviours not dealt with*”. This interviewee also recognises the emergence of mainstreaming individuals with autism in education sharing similar views to participant A. The theme of integrating individuals with autism into the community is highlighted by participant D also who highlights how individuals with autism are involved in their local communities in societies and clubs. The views offered by participant B are rooted in recognising autism as distinct from intellectual disabilities. This view is evident in this statement presented him/her:

“Well I think that the fact that it’s seen as being different from other intellectual disabilities, it’s not just being put into the same basket as everybody else and people are realising that when you are dealing with someone that is autistic it’s totally different to someone who has epilepsy or Down’s Syndrome or any other form of disability.”

Following on from researching the area of the main developments in recent years in relation to autistic adults, participants were asked to comment on how they would assess the overall developments in relation to the implementation of autistic specialised services for adults. The views shared on implementation of the main development share some positive attributes. Participant A and participant B both raise the implementation of personal centre planning which is about developing goals and working towards goals. Participant B, however, illustrates a fault in this new method

of care stating that:

“Now they are bringing in personal centre planning, at the moment it’s across the board for all clients and they haven’t actually come out with any particular literature in line which is specific to autistic clients and it really has to be looked at as a total different disability.”

Participant B also suggests that implementation of services often does not occur because training in the area is not provided to staff. Awareness amongst staff also features here in relation to the manifestation of autism. Participant B states that if training was offered to staff working with autism then a greater general knowledge of autism would be ignited amongst staff. Also this training would also lead to better practice. This concern is also mirrored by participant D who also identifies failure in appropriately training staff adequately. *“Staff need to grasp a better knowledge of what autism is and how to respond to their needs. There needs to be specialised training for staff”*. The implementation for services for children appears to have developed on a much greater scale than that of services for adults. Participant A expresses his concern about the danger of those with autism who are over eighteen years of age being the “forgotten generation.” This participant illustrates that when it comes to funding, priority is given to multi-disciplinary supports which focuses on children from 0-4 years of age. The drop in service provision for adults with autism is reflected in this quote: *“It becomes difficult to get supports for people over eighteen years of age for speech and language therapist and occupational therapists. There’s definitely a deficit in supports once people leave school”*. This view is also reflected in the comments offered by participant D, who sees those with autism over thirty years not been forgotten about, but not identified. This participant suggests that service provision for those with mild to moderate autism may receive services once they have finished schooling, however, the future for those with severe to profound autism appears bleak, as the same service provision is not available. Views expressed by participant C also identify implementation of service provision for children, with more adequate programmes in place to meet the needs of children with autism. This participant offers no commentary on the implementation of services for adults with

ASD in Irish society. The similarities in viewpoints in relation to personal centre planning and autistic adults been left out of service provision illustrates the plight that exists amongst services for adults with ASD's. Poor implementation relates back to the inconsistency and sparse developments in the area of service provision for adults with autism in Irish society.

Full Inclusion for Autistic Adults

The theme of full inclusion has emerged in society in an effort to achieve equality in society and to combat social exclusion. We now live in a society that promotes full inclusion regardless of one's ability, race or religion. Participants were asked to comment on how they perceived the concept of full inclusion in relation to adults with autism in society. This question showed very interesting viewpoints among the interview participants. The views offered by participant A illustrate elements of full inclusion but also articulates difficulties and obstacles that arise. This participant illustrates that society is playing a greater role in participating with those with disabilities. However, participant A highlights that those with autism are at a disadvantage in comparison to those with Down Syndrome, as the disability is not visual. Participant C voices this view but identifies behaviour as contributing to the failure in achieving full inclusion for autistic adults; "There's still not full inclusion. They are seen as having a mental handicap. Things such as their behaviour will always exclude them in society. Because they are the things people will not accept." Participant A suggests that a greater awareness of the disorder should be created in education, especially in second level education. The development of awareness of autism is also identified by this participant as occurring in the media. Deinstitutionalisation is also viewed as a stepping stone to achieving full inclusion, along with the development of community integration for autistic adults in Irish society. Both participant A and B recognise that there is a percentage of the population who will include people with autism to the best of their ability, but there still is not full inclusion. Participant D does not believe full inclusion is activated amongst autistic adults in society for various reasons. This interviewee highlights how early intervention has developed. However, services are not available to all children

with autism, therefore excluding individuals with autism as soon as their first years of life. The low level of awareness and knowledge of what autism is, appears to be the biggest barrier in achieving full inclusion as identified by participant D: *“Society doesn’t understand what a person with autism or intellectual disability is or the way they behave. There are an awful lot of people left out of society.”* The aim of integrating full inclusion for individuals with autism through education is also reflected in participant D’s response to the question. Participant A had similar view on this aspect of integrating full inclusion for individuals with ASDs. However, participant D identifies the importance of mainstreaming people with autism in education but states that the educational tools to do so just don’t exist. The varying views on full inclusion are not very positive for the autistic adult who aims to achieve inclusion in an excluding society.

The four interviewees were then asked to present what they believed to be challenges for service providers in incorporating the theme of full inclusion. Various viewpoints were offered in response to this question. Firstly, participant A identifies one of the main challenges of integrating full inclusion into the life of the autistic adults is the provision of resources. Participant D also echoes this concern in relation to lack of funding and resources. The view of full inclusion as interpreted by participant A is:

“If you’re taking inclusion then you’re rewarding them with opportunities within society, for example to go on a holiday during the summer, to go horse riding, to go swimming, to do P.E. Recently two of our service users went on a helicopter ride which was fantastic”.

This participant emphasises taking into consideration everything you do when you work with a person with autism. For example, when using transport consider not having the organization’s name blazing across the side of it. It is important to be less visual and treating those with autism as equal to everyone else in society. Participant A also suggest that service users be dressed age appropriately and ensure that close fit elements such as this contribute to full inclusion of autistic adults in society. Participant B holds different views to achieving full inclusion by looking at society as a whole. This participant sees people’s fear of those with autism as a challenge to

gaining full inclusion. The administration of pity as opposed to empathy for people with autism also features as a challenge. Participant B however outlines that people with autism do not see their lives as different as opposed to everyone else in society. This view is reflected in this quote: *“They’re perfectly happy with their life the boundaries they place on it and the value they place on things is completely different to ours”*. The participant suggests this is what society must understand and that those with autism have a totally different value system to those without the disorder. Views expressed by participant D highlight also the need for society to accept autistic adults for who they are. Comments offered by participant C identifies behaviours that accompany autism as giving rise to implications in implementing full inclusion. This interviewee speaks of a service user who had High Functioning Autism and was very independent. This particular service user gained employment in society. However, the autistic individual’s behaviour began to escalate and those with whom the autistic individual worked with did not understand the manifestation of autism. This service user was then placed back in sheltered employment. The participant commented on how articulate and able this autistic adult was. However, full inclusion was not achieved. Participant D acknowledges that implementation of services is not being overlooked by any specific group. This entails policy not being implemented and service provision for autistic adults being inadequate. The failure of any one group or council to take responsibility for service provision acts as a challenge for full inclusion to be achieved. The concept of full inclusion throughout the fieldwork research contains many negative aspects leading to those with autism in Irish society being excluded and their quality of life being altered.

Conclusion

The fieldwork research offered realistic viewpoints of service providers on service provision for autistic individuals. The research suggests that adults with autism in Irish society are not provided with the adequate resources to aid them in achieving to the best of their potential. The failure of the State to provide transitioning services for ASD adolescents and adults is shared by all participants. The concept of inclusion remains yet to be achieved for autistic adults as the failure to provide educational and



training services prevents many ASD adults from participating within society. The research findings outline the extensive need for advocates and advocacy groups to voice the needs of those with ASDs in Ireland. They offer a realistic insight into service provision for autistic adults within the Irish state.

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