Autism and ABA: The gulf between North America and Europe

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Abstract

Autism Spectrum Disorder is diagnosed when an individual shows specific social communication difficulties and repetitive behavior patterns. Prevalence estimations have been increasing over the past few years with rates now at 1:68. Interventions that are based on Applied Behavior Analysis are significantly related to best outcomes and are widely considered 'treatment as usual' in North America. In Europe this is not the case, instead a rather ill defined 'eclectic' approach is widely promoted. In this paper we discuss some of the roots of this gulf between Europe and North America and correct some of the misconceptions that prevail about Applied Behavior Analysis in Europe.

Keywords: intervention; scientific method; parent training; evidence-based practice; applied behaviour analysis; ABA

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The American Autism and Developmental Disabilities Monitoring Network reported estimated prevalence rates for Autism Spectrum Disorder (ASD) to be 1 in 68 (Centers for Disease Control, 2013). Similar figures are recorded in the UK and across Europe (Hughes, 2011). These prevalence rates place huge demands on health care systems. Economic costs associated with autism make it the most costly medical condition with an annual total cost of $61 billion in the USA and at least £3.1 billion per year in the UK, more than heart disease, stroke and cancer combined (Buescher, Cidav, Knapp, & Mandell, 2014).

The common goal of autism interventions is to address quality of life issues by improving skills that can remove barriers to learning and facilitate independence; best practice utilises methods based in Applied Behavior Analysis (ABA) (Anagnostou, Zwaigenbaum, Szatmari, 2014; Maurice, Green, & Fox, 2001). In fact, there is a highly statistically significant relationship between ABA-based interventions and optimal outcomes (Fein et al., 2013; Orinstein et al. 2014). ABA-based interventions use a data-based decision making model of program delivery to ensure that interventions are holistic and person-centered; this means that the choice of intervention depends on the behaviors to be established and on the progress attained at any point in time (Maurice, Green, & Luce, 1996). Children who are in an intensive early ABA-based program typically receive at least 25 hours per week (Myers & Johnson, 2007; National Research Council, 2001; New York State Department of Health, 1999).

The focus of this paper is to draw attention to the kinds of issues that have influenced

Governmental policy support for ABA-based interventions in the USA and Canada and to examine the obstacles for the uptake of ABA in several European countries.

Gulf between Europe and North America

In the USA, and based on 30 years of research at the time, the Surgeon General (1999) recommended ABA as basis of intervention. Since then, ABA-based interventions have been considered as medically and educationally necessary and are considered 'treatment as usual', funded through government or health care systems in the vast majority of States (38 States at the moment), federal bodies, such as the Office for Personnel Management and Medicare, and many multinational companies, such as JPMorgan Chase & Co., Microsoft, Apple, Goldman Sachs, Intel, etc. (Autism Speaks, 2014). Board Certified Behavior Analysts (BCBA; www.bacb.com) are the professionals who supervise these programs (frequently within licensure laws).

> … ABA is not a stagnant, single continuum of prescribed methods but rather emphasizes the use of methods that change behavior in systematic and measurable ways with an emphasis on analysis, replication, social importance, and accountability. ABA includes a large number of conceptually consistent techniques that can be used in various combinations across many different contexts whilst remaining abreast of developments in biology, medicine, and neuroscience (e.g., dietary requirements). (Anderson & Romancyzk, 1999, p.167)

Agreements to introduce laws that mandate the health care system to cover autism interventions based on ABA in each of the 38 States in the USA have arisen from intense deliberations about the quality of the research evidence (Unumb, 2013; Hagopian & Hardesty, 2014). This evidence is substantial and includes results from

1. over 2000 replicated single system design studies
2. Randomised controlled trials (RCT)
3. Meta analyses
4. Sequential meta analyses
5. Systematic reviews
6. Neuroscience (plasticity of brain)
7. Social validity measures
8. Cost – Benefit analyses (see Larsson, 2013 for extensive list of references)

Similarly in Canada, ABA is viewed as providing the foundation for effective treatment and ABA-based services are available, although the extent of coverage varies across Provinces (Autism Society Canada, 2010; Autism Now, 2014).

In contrast to North America, ABA-based interventions are not endorsed by Governments across Europe. A paper in the Autism Europe newsletter serves as a good example of how the evidence for ABA-based interventions is ignored in Europe (Howlin, 2013). While Howlin (2013) refers briefly to Lovaas (1987), who is credited with the first large scale study on using ABA-based interventions for autism, her discussion is devoid of any reference to the extensive body of evidence supportive of the application of behavior analysis.

This omission is all the more remarkable when you consider that Howlin's own research (Howlin, Magiati, & Charman, 2009) showed that on average children who received ABA-based interventions did much better than those who received eclectic 'treatment as usual'. While Howlin et al. noted that there were considerable benefits at the group level, they focused much more intensely on the fact that, on an individual

level, not all children benefited as much. In other words, these researchers focused on the relatively short 'low impact tail' of the distribution curve rather than on the large average or the significant 'high impact tail' (cf., Dillenburger, 2014). These findings are quoted frequently in Europe as an argument to withhold support for ABA-based interventions (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010).

In a European context where training in behavior analysis to international standards is not commonly available, it is not surprising to find that ideological assumptions can interfere with an objective appraisal of empirical data (Fazzio, 2014; Keenan, Dillenburger, Röttgers, Moderato, 2010; see also video testimonials by professionals from Iceland, Italy, Sweden, and the Netherlands at STAMPPP, 2014). In a recent 40-year follow-up study of children diagnosed with autism in the 1970s (Howlin, Savage, Moss, Tempier, & Rutter, 2014), Howlin's personal negative opinion about ABA was again in sharp contrast to her own findings that showed extremely poor long-term outcomes of eclectic school intervention, i.e., 75% of the adults (average age 44 years) had plateaued at their 3-year-old levels while 25% of these adults could not even be assessed due to lack of communication skills and challenging behaviors. Howlin et al. (2014) concluded that, "[a]lthough many attended [eclectic] specialist autism schools as children… none had access to the intensive, early behavioral programs, that are available today and which are claimed, by some, to have a significant impact on IQ and long-term outcome" (p. 56).

This indirect endorsement of ABA by Howlin et al is misleading because in fact, only one third (32.3%) of young children with ASD (aged <6 years) in Europe receive behavioral intervention of any type, ranging from 8.6% in the Czech Republic to

80.6% in Romania (Salomone, Beranová, Bonnet-Brilhault, Lauritsen, Budisteanu, Buitelaar, et al., (under review). Salomone et al. found that the average number of hours per week was 8.69 (range 0.64-23; SD 9.80). However, given that these data are based on an online survey that was completed by-and-large by well-educated parents (a common proxy for Social Economic Status; SES), it is likely the behavioral interventions are much scarcer for most children with autism in Europe, especially those living in deprived areas. When effective behavioral interentions are not supported by established academics, and consequently not implemented in local health and education systems, the real figures show considerable inequalities related to parental education and social economic status.

Cultural issues

Apart from academic confusion (Baird, 2014) and ideologically motivated omissions (Howlin, 2013) or distortions (Howlin, Magiati, & Charman, 2009; Howlin et al., 2014), there are other issues that impact directly on efforts to disseminate accurate information on the effectiveness of developing interventions that stem from ABA. One of these issues is embedded in difficulties arising from the transmission of research findings from one culture to another (Dillenburger, McKerr, & Jordan, 2014). It is customary in Europe, for example, not to involve behavior analysts in the writing teams of Government reports regarding autism interventions (Keenan, 2014). A good example is the Linea Guida 21, a guideline on effective treatments for autism recently published by Italian Istituto Superiore di Sanità (ISS, 2011), (a research branch of the Italian Ministry of Health). This guideline asserts that behavioral interventions are most effective in autism treatment. However, because no behavior analyst, nor academic or professional trained in ABA, was on the scientific board that evaluated the

research (Moderato, 2012) the guideline report contained serious examples of confusion between science, procedures, models and protocols for intervention (see below).

Misrepresentations of ABA abound not only in government reports but also in the media and social media (Baron-Cohen, 2014; The Skeptical Advisor, 2014) and even more worryingly in some peer-reviewed journal articles (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2007). ABA has been caricatured beyond recognition (Jordan, 2001), mocked (Kaufman, 2013), branded controversial (Lambert, 2104; Scott, 2014), related to post-traumatic stress disorder (PTSD; Research Autism, 2014) and attacked for promoting a 'normalization agenda' (Lambert, 2014; Milton, 2014). Maurice (1999) captured these absurdities and controversial misrepresentations as follows:

> Dozens of pseudo-scientific books and articles out there describe it [i.e., ABA] as child abuse, a squelching of the spirit, a crushing of the soul. Treating the symptoms and not the "root cause," whatever that might be; a denial of the self, cruel, manipulative, dehumanizing, punishing, controlling; etc. etc.
>
> Moreover, even when people do not attack behavior analysis, they make glaringly ignorant statements about it, like "Oh yes, that's where they do discrete trials for forty hours a week." Or, "behavior management is for really low functioning kids. (p. 3)

To highlight the significance of common caricatures of ABA in autism intervention, Figure 1 offers an accurate, albeit bare bones summary of how the scientific method guides decision making in an ABA program.

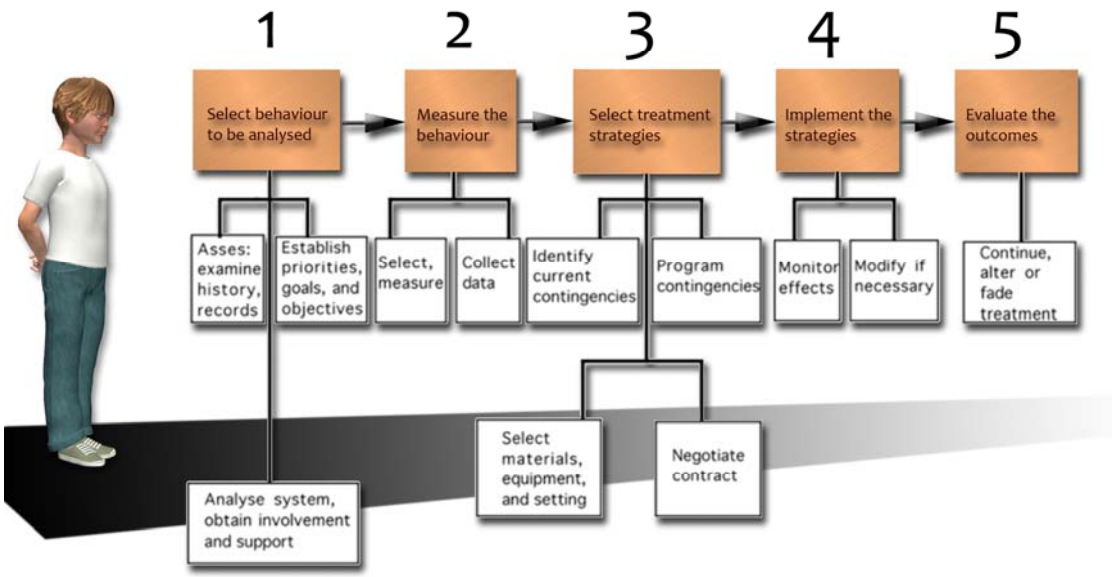

Figure 1: Five basic steps in using the Scientific Method in ABA (adapted from Reese, Howard, & Reese 1979, p. 34).

Step 1: Select behavior to be analysed

A decision is made about which behaviors should be analysed, i.e., targeted for change. For younger children with autism, this decision involves the family and professionals working as a team to determine priorities and goals to be achieved. Older children and adults are involved themselves in decision making about which skills would enhance their quality of life, e.g., the development of social or employment skills.

Step 2: Measure the behavior

As with any science, decisions are made about how best way to measure the behavior which defines the goals of an intervention, e.g., is it more important to engage in a

behavior more often (and thus measure frequency) or to engage in a behavior for longer periods of time (and thus measure duration); or is it important to engage in the behavior quicker (and thus measure interresponse time or latency) or to engage in a behavior more 'smoothly' (and thus measure fluency). Measurement is essential for monitoring progress and for tailoring an intervention to the needs of an individual. Training in the analysis of behavior provides skills in the operational definition of psychological terms. This skill set provides measurement strategies that bypass misleading issues arising from the use of summary labels and explanatory fictions (Chiesa, 1994; Cooper, Heron, & Heward, 2013; Moore, 2008).

Step 3: Select treatment strategies

Progress of course, depends on which intervention you use. This in turn depends on the nature of the goals specific to each individual. Interventions in ABA are based on existing principles of behavior that have been uncovered by the natural science of behavior analysis; in other words, they are based on the findings of how behavior works. Behavior is defined holistically as the interaction between the biological organism and the environment. It is understood that this interaction involves a continuous flow of adaptations and therefore interventions have to remain flexibly attuned to changes as they occur. The intervention strategy, then, depends on individual circumstances and it changes dynamically with behavioral change and progress.

That said, there have been some issues about particular *procedures*, especially if they included the use of aversives. Lorna Wing (1966), for example, recommended a 'smack, a loud firm 'no' or putting the child out of the room' (p. 272) for children with

autism. Schopler et al. (1980), who devised the commercial package called TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children) described the use of 'aversive and painful procedures' such as meal deprivation (p.121), 'slaps or spanks on the bottom' (p.121), and 'electric shock, unpleasant tasting or smelling substances' (p.122) as methods that could be used if other methods do not work. For some unknown reason, though, it has been Lovaas who was much more heavily criticized for using these methods than either Wing or Schopler (Webster, 2011).

The discussion about the use of aversives should be viewed in historical perspective. In the UK, the 'cane' was used to inflict corporal punishment in mainstream schools for all children, until it was finally outlawed in 1987! In private schools corporal punishment was not banned until as recently as 1999 in England and Wales, 2000 in Scotland, and 2003 in Northern Ireland. Physical punishment of children by their own parents is still not illegal in many parts of the world. This is by no means a justification for the use of aversives, on the contrary (Dillenburger & Keenan, 1994; Goupillot & Keenan, 1995), but it helps to put into context the allegations that the use of aversives was a feature peculiar to behavioral interventions in the 1960s. Sadly, corporal punishment was generally part of life then. Corporal punishment and the widespread use of aversives are no more advocated in ABA than they are accepted anywhere else in modern day society (Sidman, 2000; see also ABAI, 2014, for a position statement on Restraint and Seclusion).

Step 4: Implement the strategies

This involves the application of the chosen intervention strategy, and data collection to monitor whether the goal is being reached. Data collection shows, for example, whether progress is being made towards the goal, even if this progress is slower than anticipated. In ABA, data collection takes place continuously throughout the intervention, not merely at the end.

Step 5: Evaluate the outcomes

This is integral to the person/child-centered focus of ABA in that it demands adjustments to be made depending on the progress of the individual when using the selected intervention. At its most basic, if the intervention is not working, then it is adjusted until the targeted change is achieved, i.e., the barriers to quality of life are removed.

Across all of these steps there is nothing that is cruel or controversial about applying the scientific method. Even parents who are not specifically trained in ABA find the steps coherent and 'common sense' (ABA4all, 2014). At its most basic level, behavior analysis simply makes explicit the principles of behavior that operate implicitly in everyday life (Keenan & Dillenburger, 2014). The emphasis here is the word 'analysis': "Such an approach entails far more than changing behavior. It entails understanding behavior and the complexity of the interactions between individuals and their environment, particularly their social environment." (Walsh, 1997, p. 101). So where is the problem? How come the outrageous caricatures persist and impede the uptake of an effective science?

Communicating the practices of a natural science

One of the difficulties with understanding the 'real' ABA is the language of the science itself. There are a couple of issues at work here. Figure 2 illustrates one aspect of the problem. The left-hand panel shows a surgeon operating on a child while at the same time a group of medical students are watching intently. Imagine that the surgeon is providing a running technical commentary on every incision and every decision he makes regarding his manipulation of the child's internal organs. He does so to ensure that his students will be able to replicate the operation with the same degree of skill he is showing them.

Figure 2. Different perspectives of a professional at work.

Left panel: A surgeon is giving a running commentary on his operation to medical students.

Right panel: The same commentary is given to parents of the child undergoing the operation.

Now imagine we could rewind the clock and repeat the operation. This time though, the audience is changed (right-hand panel). This time the parents of the child (lay person) watch the surgeon. It is easy to see why the parents and others not trained in a natural science might view the words of the surgeon as overtly technical or even cold and uncaring. At issue here is not the skill of the surgeon, but the level of understanding in the audience. This is an unfortunate problem because the surgeon is

not a cold-hearted individual and the science that guides the operation is acutely concerned with human welfare and wellbeing[1]. The problem is one of how to share sophisticated knowledge and skills with lay people who have not received training in the science.

The same is true for ABA. However, training in the science of ABA to international standards is not available in most European countries (BACB, 2014; Chiesa, 2001; STAMPPP, 2014). For instance, Dillenburger, Röttgers, Dounavi, et al. (2014) noted that professionals who are typically involved in autism diagnosis and treatment (i.e., paediatricians, psychiatrists, social workers, speech and language pathologists, occupational therapists, teachers, as well as clinical and educational psychologists) generally receive very little or no training in autism or ABA during their qualifying training.

It is conceivable, therefore, that professionals who are untrained in a natural science of behavior may come to conclude that they are watching the practices of a cold-hearted doctor and do not appreciate the precision and sophistication of his skills. Yet, without the skills of the doctor or scientist, and subsequently the skills of next generation of students of the science, the child's prognosis would be very poor; similarly, if the intervention were to be conducted by someone not appropriately skilled, it would most likely not be effective.

[1]This example is not meant to imply that a medical model is being promoted. It is merely an example of the problems caused when technical terms from a science are misunderstood by those not trained in that science.

To some extent, misrepresentation of ABA is to be expected when training is not available. However, there is another more pernicious and subtle way to undermine the potential support by governments for training in ABA in Europe. Keenan, Dillenburger, Moderato and Röttgers (2010) drew attention to the damaging effects of the privatisation of science by behavior analysts in a context where governments and parents cannot discriminate between commercial products and the science that lead to the development of these commercial products. For example, Early Start Denver Model (ESDM), which is now popular in Italy, is based on behavior analytic principles. Behavior analysis is a science, ABA is an applied science or technology, ESDM is one of the many possible models that apply the principles (Moderato & Copelli, 2010 a,b). The same is true for Positive Behavior Support (PBS) and the Picture Exchange Communication System (PECS), both of which are widely supported in the UK and elsewhere in Europe. It would appear at times that the commercial interests in the promotion of a 'product' come into conflict with efforts to ensure that ABA is exalted as the foundation of the product.

The state of the science in Europe

UK & Ireland

The historical legacy of 'behavior modification' without functional assessment or functional analysis (i.e., the rush to implement behavior change procedures without appropriate analysis of the function of behavior, Walsh, 1997) has resulted in a blinkered view of the true nature of behavior analysis (Keenan, 2004; NAS, 2014; NICE, 2013), including confusion over how the term 'behavior' is viewed by behavior analysts (see comments to Lambert, 2014). A good example comes from a major charitable organization, Research Autism, that informs the National Health Service on

autism interventions:

> Because there are many different interventions, programmes and techniques used to help individuals with autism which incorporate the principles of applied behaviour analysis it is not possible to provide a ranking for applied behavioural analysis as a whole. (Research Autism, 2014)

The suggestion here that ABA is simply a collection of procedures/techniques is a theme that is repeated across Europe and has lead to the marginalization of a whole science (Odom, Hume, Boyd, & Stabel, 2012). In marked contrast to the conclusions of Research Autism, Hagopian and Hardesty (2014) provide a comprehensive list of other organisations that were able to make recommendations about ABA. In Ireland, North and South, the predominant view also is that 'ABA is simply one of a number of techniques' provided within an eclectic model of service provision (Keenan, 2014; McCormack, 2014). To complicate matters, the list of techniques includes a serious category mistake (see below) such that ABA and PECS, for example, are each considered techniques:

> As it stands, the ABA experts are uniformly of the opinion that what the government provides under the eclectic model is not ABA in any sense of the word. What the department of education is doing is the equivalent of ignoring the advice of heart surgeons on heart surgery and instead taking advice from GPs and dentists. (Irish Election, 2014)

Germany

In Germany, Applied Behavior Analysis is neither officially recognized nor supported. The responsibility for the care of persons with autism lies with both the health and the social care sectors. Diagnosis of ASD and of comorbid disorders is the responsibility

of the health care system, but due to a court decision in 2009, ASD is classified as a static, 'lifelong' condition that does not respond to intervention and therefore does not legally qualify for treatment. As a result, German healthcare (i.e., health insurance) are not obliged to cover autism treatment. In reality, some healthcare funding is available for individual and group programs for adolescents and adults with high-functioning ASD and Asperger's Syndrome. Intensive programs for children and persons with low-functioning ASD are not funded, despite the fact that professional medical guidelines recommend behavioral interventions as the only evidence-based interventions2.

Where they are available, autism interventions in the health care sector are delivered or supervised by medical or psychological professionals, who have recognised qualification in behavior therapy. The term "autism specific behavior therapy" (AVT) has been established for the methods used with individuals with autism. Autism specific behavior therapy is not the same as ABA and does not necessarily meet the quality standards of the Behavior Analyst Certification Board.

Early or intensive ASD interventions are the responsibility of the social and disability care system. This system is organized on a local level without federal or Länder/State standards. Decisions regarding intervention method, intensity, and staff qualification are made by public servants with administrative qualifications and/or by social workers most of whom have little or no training or experience in the field of ASD.

1. 2 Dt. Ges.f. Kinder- und Jugendpsychiatrie und Psychotherapie (Eds.): Leitlinien zur Diagnostik und Therapie von psychischen Störungen im Säuglings-, Kindes- und Jugendalter. Tief greifende Entwicklungsstörungen (F 84) in: Deutscher Ärzte-Verlag, 3. überarbeitete Auflage 2007, S. 225 - 237

While there are a small number of autism-specific institutions who deliver behavioral programs, the majority of these centers prefer an "eclectic" approach, including nonspecific, psychodynamic, and/or complementary and alternative medical interventions that are not evidence-based. The leading parents' advocacy group Autismus Deutschland strongly opposes the focus on evidence-based interventions, in fact, they view them as 'restriction'. However recently, due to extensive lobbying from experts as well as parent groups, there are some signs of development. Recommendations and guidelines are about to be published in some German Länder/States by the social and disability services that are based on evidence in favor of behavior interventions3.

There are no courses in German universities that teach full ABA curricula because a degree in ABA would not legally be considered as a healthcare profession. In addition, curricula in most psychology and medical courses do not prepare students for autism specific interventions (Dillenburger et al., 2014).

The University of Applied Sciences in Münster is the only German university that offers undergraduate and postgraduate courses in "autism specific behavior therapy" in cooperation and with the support of international partners and the leading association of behavioral psychotherapists (Deutsche Gesellschaft für Verhaltenstherapie; DGVT) offers a (voluntary) postgraduate staff qualification in "autism therapy" with a strong behavioral focus.

3 Landschaftsverband Rheinland und Westfalen-Lippe (federation of city councils in the state of Northrhine-Westphalia): Recommendations for interventions for children and adolescents paid for by the local social care authorities, due late 2014.

There are a few local initiatives in Germany, such as the Association for Behaviour Analysis Deutschland (ABA-D), that are either supported by ABA professionals trained abroad or by psychological or psychiatric staff with extensive experience in the field. In some places, early behavioral interventions are delivered to a limited number of families under a variety of different supervision and funding arrangements, including not-for-profit as well as private enterprises.

Statutory education in Germany is governed by Länder/States and therefore the school situation for children with autism varies considerably. For the most part, educational staff and teachers tend to reject behavioral interventions, whereas special needs education staff is more open.

In sum, Germany is still considered a 'developing country' in terms of autism therapy. Progress is slow and the potential of the majority of persons with ASD remain untapped and their quality of life and chances for independent living remain unnecessarily limited.

Greece

In Greece, the first BCBA offering ABA-based services to families of children with ASD appeared on the BACB registry in 2009, and the panorama has not changed a lot since then. Instead, an internet search reveals that there is an abundance of professionals who are not BCBAs offering ABA as one option within an eclectic model. This lack of quality in the behavior analytic services feeds the debate about whether ABA-based treatment is humane, can achieve generalization, or takes into account different individual needs. This situation represents a major obstacle in helping

children with ASD reach their full potential because it misleads parents, naïve professionals, and the health system overall.

The difficulties experienced by the Greek economy place a further burden on families, who up to 2011 received a maximum of 527€ per month by the state (Joint Ministerial Decision Γ4/Φ.12/οικ.1930/1982; Joint Ministerial Decision Π3α/Φ.18/Γ.Π.οικ. 63731/2008) but in 2013 their benefits were limited and only applicable only to individuals diagnosed with at least 80% of impairment (Joint Ministerial Decision Π3α/Φ.18/Γ.Π.οικ. 63731/2013). These changes in legislation together with increased unemployment and decreased salaries have undoubtedly limited access to effective treatment. Additionally, given that legislation in Greece does not accommodate ASD separately, but instead describes the necessary education and treatment for all children with special needs, Applied Behavior Analysis is not even mentioned in any official documents. Instead, traditional eclectic interventions delivered by psychiatrists, psychologists, speech and language therapists, special teachers and occupational therapists are often prescribed and partly funded by the public health system in educational or home settings (Ministry of Interior, Public Administration and Decentralization. General Secretariat of Public Administration and Electronic Governance. General Directorate of Administrative Organization and Procedures, 2007). Official documents repeatedly mention “early intervention” and “inclusion” as goals but these are to be achieved by state teachers who do not have training in Behavior Analysis (Law 3699/2008).

Notwithstanding this devastating picture, in 2009 the conference of the European Association for Behaviour Analysis was held in Greece, and thanks to the efforts of a

small number of behavior analysts, both academics and clinicians, there has been an increase in the number of students learning about ABA at undergraduate and postgraduate level through Greek textbooks (e.g., the first comprehensive textbook on Behavior Analysis in the Greek language was published by Mellon in 2005). Since then, an increase has been observed in the number of professionals who receive supervision by a BCBA or BCBA-D, and an increase in the number of families and professionals who can now access accurate information on the science (e.g., Dounavi,2013). Although there is a long and difficult journey ahead, there is hope that knowledge about the applications of ABA will reach the public eventually.

Iceland

In Iceland, ABA based intervention for pre-schoolers with ASD started as a research project in 1995, and in 2000 a decision was taken at the State Diagnostic and Counselling Centre (SDCC), an institution that serves the whole country, to inform parents of newly diagnosed young children about this option in addition to the prevailing eclectic approach. Today, more than half of these parents choose an ABA program and attend courses and workshops provided by the SDCC. The legislature has provided young children with ASD, as well as other children with special needs, the rights to services at the pre-school level under the guidance of specialists (The Pre-School Act, no. 90/2008). Provisions are made for special education for a specific number of hours per week depending on the child´s needs and condition. There are, however, no official guidelines or recommendations available regarding teaching methods, giving those who are responsible for providing the services in the schools the freedom to follow their own preferences.

The uptake of ABA has not been painless and is still met with scepticism by some service providers, who refuse to accommodate it due to ideological reasons, and the well known comparison with dog training is still heard. Misinformation about ABA is not surprising when considering the education and training of teachers and other professionals who are directly involved with teaching children with autism. A brief survey conducted in 2013 of the content of their education at the University of Iceland, indicated that they have not been provided with a theoretical background in behavior analysis, nor training in the specialized and evidence based methods that are needed in order to teach children with special needs in an effective way (Sigurdardóttir, Pétursdóttir, Jónsdóttir, & Magnússon, 2013).

There are only five BCBA´s in Iceland, and three of them supervise programs for children with ASD part of their time. In addition, there are a handful of supervisors with some education and extensive experience in behavior analysis, but without certification. Although the services have suffered from too few qualified supervisors who can meet increasing requests from parents for an ABA based program, there is a reason for some optimism. A master's program has recently been established at Reykjavik University that offers the courses required for a BCBA certification. Many school principals, both at the pre- and primary school level, have supported the uptake of ABA for students with ASD in their schools, even though most of those who provide direct services (teachers and trainers) are still not receiving adequate training and supervision. However, one school is collaborating with credentialed ABA consultants from USA. Another example is a pre-school in Reykjavík that is now aiming at being recognized as specialized in ABA based intervention, where plans are being made to collaborate with the universities and experts in the field, and to secure

supervision from BCBA´s. This project holds the potential to become a training center for those who want to pursue certification in behavior analysis, as well serving as a model for other schools.

Italy

In Italy the welfare system provides supports and services free of charge to children with disabilities and their families. This is a general statement, the way of applying it depends on the regulations of each regions. Due to the lack of an Autism Reference Centre, like those that exist for other conditions (e.g., oncology) the waiting list to have a diagnosis from a child psychiatry department is long, 6 months to 1 year or more. Following a diagnosis of ASD, the child is generally assigned to an eclectic treatment: 1 or 2 session a week with a physical/psychomotor therapist and a speech and language therapist. With very few exceptions, a board certified behavior analyst, or someone with equivalent qualifications, is not available in the public health service. This means that the parents, once they realize (via some unofficial or informal way) that ABA-based treatment is what they need and what they want for their child, they must find and recruit a private ABA consultant. The cost of doing this is partially (20-40%) reimbursed in some regions, like Veneto and Puglia, up to €5200 in Tuscany, according to the different regional health systems. The criteria for acknowledging who is to deliver ABA-based interventions is very loose and confused.

As an alternative to obtaining behaviorally based interventions, the family can take the child to a habilitation center or private clinic, very few of which deliver true ABA-based treatments. The interventions are carried out in the center, and should follow the Linea Guida 21 mentioned above. Unfortunately, the Italian Parliament has not yet

made a general law to regulate the field and force every single ceinter and department to follow the guideline and provide only interventions based on science and best practice. The lack of an overall law allows methods such as 'facilitated communication' to survive in some parts of our country. In Lombardy, in 2011 IESCUM and FOBAP-Anfas (an historical association for disabled people – AAIDD like), started a pilot project, funded by the regional government, to provide ABA interventions, for kids from age 2 years to age 16 years: 4 two-hour sessions plus two hours parent/teacher training for children 2 to 7; 2 two-hour sessions plus two hours parent/teacher training for kids 7 to 12, and so on. The results are very encouraging in terms of effectiveness with a reasonably limited use of human resources. Sustainability of the interventions is (will be) indeed one of the main problems to face once people ask for early or intensive ASD interventions4.

In parallel with this pilot project, children are included in regular preschool class, according to Italian law for inclusion, with a special support teacher to work with the child. This is a great opportunity for development for the child, especially if the special support teacher is trained in the principles of behavior analysis and the whole school collaborates with the ABA consultant. The acceptance of ABA within mainstream pedagogy, however, is very low; the situation is somewhat better, with many caveats, within special education pedagogy. One of the reasons for this state of affairs is the negative, though not unexpected, side effect of the publication of Linea Guida 21.

Due to the increased demand of EIBI and the lack of available certified ABA consultants (there are only about 40), some private agencies organize short courses,

4 Sometimes packaged as Early Intensive Behavioral Intervention (EIBI)

with the promise of training people as ABA-VB consultants. This is, of course, false advertising. What is even worse, though, is that some state and private universities advertise Master programs in ABA where the science of behavior analysis has no home, and EIBI disappears in an ocean of eclectic interventions.

Netherlands

On average, children in the Netherlands are diagnosed with ASD from the age of five years (Nederlandse Vereniging voor Autisme, 2008; Peters-Scheffer, Verschuur, Huskens, & Didden, 2014). As a consequence, these children receive treatment much later than is recommended (Warren et al., 2011). Some children with ASD enrol in special classes (about 23% in less intensive special education and 35% in intensive special education), while others (about 39%) attend a class where there are other children with developmental disabilities such as Down syndrome, learning disabilities and/or an intellectual disability, and/or behavioral challenges (Nederlandse Vereniging voor Autisme, 2008). Due to recent changes in educational policy in the Netherlands (Rijksoverheid Nederland, 2013; Dienst Uitvoering Onderwijs, 2010), children with ASD who have an average or higher intellectual and linguistic ability are increasingly attending regular education. It is uncertain to what extent school placement scores predict later social and economic functioning for children with ASD, however, there is some evidence that school attendance and increased social interaction with peers and adult educators provides them with more opportunities to prepare for the future (Eikeseth, 2009; Matson & Smith, 2008; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Reichow & Wolery, 2009; Smith, Groen, & Wynn, 2000). Currently, this outlook is rather bleak in terms of employment, housing, and relationships (Howlin, et al., 2014; Parsons et al, 2013).

Dutch teachers are increasingly confronted with a three-fold set of demands: (1) increasing number of pupils in their class (currently, on average 30); (2) increasing heterogeneity or diversity of the pupil population, behavioral and/or intellectual challenges; (3) increasing responsibility of educational and care provisions for all pupils in their class due to *Passed Onderwijs*/Inclusive Education, which is currently being implemented (Dienst Uitvoering Onderwijs, 2010). In other words, teachers are expected to cater for the educational and care needs of all pupils in their class. However, teachers are only sparsely equipped with evidence-based tools to meet these expectations and to provide adequate and sufficient support for pupils with special educational needs, including those with ASD (Neidt & Schenk, 2012). In addition, other barriers to implementation of evidence-based practice informed by ABA include incompletely developed interventions that have limited empirical evidence to their effectiveness and implementation of ABA-based interventions by professionals who have not received accredited ABA training; after all, to date, in the Netherlands no higher education and/or training is available for those interested in ABA. To complicate matters, Dutch parents of children with ASD are mainly informed about psycho-education and pharmacological treatment options following diagnosis (Neidt & Schenk, 2012; Schothorst et al., 2009), receive limited information regarding evidence-based interventions in other countries and continents (Peters-Scheffer, 2013). To illustrate, a recent Dutch guide for the multi-disciplinary diagnosis and treatment of adults with ASD (Schothorst et al., 2009) claimed that there is no evidence that outcomes for people with ASD in the long term are significantly better following training programs during childhood (Kan et al., 2013).

Since few children in the Netherlands are engaged in EIBI programs, it will take many years before professional educators and parents are properly informed about ABA-based intervention alternatives. The knock-on effect, of course, is that given the shortage of appropriately educated and trained professionals, it will also take a long time before large-scale applied research within school settings can demonstrate that ABA-based interventions are effective, regardless of whether these are implemented at preschool age or before; as long as implementation is done competently and completely.

Spain

The group initiated by R. Bayés gave rise to a first generation of behavior analysts in Spain that is still active today in academia (Bayes, 2003). During the 1970s, they authored the first behavior-analytic studies to be conducted in the country (e.g., Bayes, 1972) and promoted Spanish editions of some behavioral classics (e.g., Skinner, 1952/1977, 1974/1977). Interestingly, autism services developed somewhat independently from the university setting, where the experimental analysis of behavior and clinical applications for adults and typical children have received more attention (e.g., Ardila, 1998; Frojan-Parga, 1998; Luciano, 1996; Pellón & Blackman, 1987; Vallejo & Ruíz, 2000; see also Cruz, 1984). Applied research with children with autism developed significantly later and still today is clearly underrepresented – one of few active research team is led by Dr. Luis Antonio Perez-Gonzalez at the Universidad de Oviedo.

The first applied program for children with ASD offering behavioral services was the *Fundación Planeta Imaginario,* established in Barcelona under the influence of the

Lovaas replication study. The program continues to be one of the leading ABA services in the country. Currently, there are some ten applied programs and a similar number of behavior analysts working as private consultants. A number of these professionals have completed ABA Spain's BACB-approved sequence (est. 2007) and offer supervised fieldwork opportunities as part of ABA Spain's approved practicum (ABA Spain, 2014). The sequence has helped to disseminate BACB credentials, which continue to gain momentum. Seven of the nine BCBAs registered in Spain have undergone this sequence and a number of international students have also become board-certified. The sequence is positioned within the top-ten online programs with a pass rate over 70% in 2013. ABA Spain has also been critical in facilitating (a) the translation of reference materials into Spanish (e.g., Miltenberger, 2013), (b) the translation of BACB exams into Spanish, (c) the recognition of the BACB credentials by the Spanish *Colegio de Psicólogos*, and (d) the development of a consortium of applied programs offering practicum placements in Spain and the United States (Virues-Ortega, Shook, Arntzen, Martin, Rodríguez García, & Rebollar Bernardo, 2009).

Yet, in spite of these promising signs, the situation for families of children with autism is somewhat disheartening. Behavior analysts may assume less than 1% of the 7000 new cases of autism diagnosed every year in Spain.5 Moreover, ABA services are not covered by the health or education administrations. While in a few documented exceptions a court has mandated that a particular client "should receive intensive behavioural intervention," services are almost in every case paid by the families

5 Estimation based on Center for Disease Control prevalence rates interpolated to the Spanish child population for 2010; sources: CDC and INE.

privately (personal communication with J. J. Carnerero, clinical director Centro Al-Mudarïs, October 16, 2014). A few creative alternatives have been tried in recent years. For example, the *Escuelita de Ilusiones* school in the Canary Islands (*fundailusiones.es*) has transitioned from a non-for-profit project into an official special education school. The school is government-funded but yet run privately.

In sum, greater presence in academia and greater advocacy in the public arena continue to be important challenges in the agenda of behavior analysts in Spain.

Sweden

In Sweden, the welfare system provides supports and services free of charge on a needs basis to children with disabilities and their families. Following a diagnosis of ASD the child and parents are assigned to a multi-professional team which may consist of a psychologist, special educator, speech language therapist, social worker, occupational therapist and/or physical therapist any of whom may or may not also be a board certified behavior analyst or have equivalent qualifications. In parallel with this, the preschool in which the child is enrolled obtains central funding from the local education authority to employ a para-professional (trainer) to work with the child (see Eikeseth et al., 2012).

In regard to obtaining behaviorally based interventions (focused or comprehensive), the family, child and trainer travel to the habilitation ceinter on a regular basis to obtain supervision, review goals, model and role-play interventions. The interventions, however, are carried out in the preschools and home, and it is extremely rare that habilitation specialists are actually able to make onsite treatment fidelity visits. It is

within this sphere between habilitation and preschool that the complex mechanisms within a dual service system come into play. For example, the National Health Care Law (Hälso och sjukvårdslagen, 1982: 763) highlights the importance of personnel within the health care system (e.g., habilitation) providing interventions based on science and best practice. The Swedish habilitation administrators recommend early (as soon as ASD is identified), comprehensive and intensive, behavioral interventions (Bromark, Granat et al, 2012). However, while evidence and best practice are mentioned in the Swedish Education Act (Skollagen, 2010:800) there is no definition of these terms and consequences are not provided for preschools or schools for not providing evidence-based interventions. Parents not obtaining evidenced-based interventions cannot pursue disputes with educational authorities through court adjudication and neither formal nor informal mediation is mentioned by the School Inspection or the School Board of Appeal as an alternative to adjudication. Lack of guidelines might also explain in part how methods such as 'facilitated communication' surface in some parts of Sweden (see Dagens Nyheter, 2014).

There are also philosophical perspectives engrained in the Swedish pedagogical discourse that further distance the acceptance of ABA from mainstream pedagogy. For example, in an article in Pedagogiska Magasinet (Englund & Engstrand, 2011), a teacher union magazine with approximately 200, 000 subscribers, there was an illustration depicting children as puppets, helplessly controlled by a behavior modifier. This illustration won the best illustration prize 2012. The article warns against the 'Return of Behaviorism' and argued that behavior modification may have a place in psychotherapies for phobias but not with in the educational system. It was said that behavior modification deviates from current pedagogical as well as developmental

theories where there is an emphasis on mutual respect for the relationship between educator and student/child for the importance of learning and development. Also, there was doubt whether programs from the American context with different historical and relationship ideologies can automatically be transferred to a Swedish context. The Swedish National Curricula for preschool highlights the importance of democracy, every child's right to express their own opinion, and make choices, that preschool should prepare all children for lifelong learning, be enjoyable, safe, and provide a rich learning environment which is built on the child's experiences, interests, needs and opinion, and free of any kind discriminatory influences (Lpöf, 1998 revised 2010). Whilst there can be little argument against the goals in the text, there are differing epistemological traditions between the public health sector (e.g., habilitation) and local education authorities (e.g., preschools) on how to build on a child's experiences, interests, opinions etc. Possibly reflecting the effects of epistemological discrepancies at the heart of this dualistic system, Zakirova Engstrand and Roll-Pettersson (2012), in a pilot study concerning preschool teachers attitudes to the inclusion of children with autism in a middle size municipality, found that participants showed neutral attitudes towards inclusive practices and only 43% reported that supports for the child with autism were based on ABA. In addition, the average number of hours per week in which they worked one-on-one with the child was 2.56. In sum, it appears that the epistemological and philosophical gulf between these sectors is in need of bridging, which at bare minimum should include recognition of applied behavior analysis in mainstream pedagogy and special pedagogy (see Roll-Pettersson, Ala i Rosales, 2009; Käck, Roll-Pettersson, Ala i Rosales, et al. 2014). In light of parents' lack of a legal mandate, there is also a need for inter-organisational contractual agreements

guaranteeing children with autism the right to appropriate and individualized ABA interventions implemented with integrity.

Despite these obstacles, Stockholm University offers an inter-departmental graduate level course sequence in behavior analysis approved of by BACB in which half of the sequence is given through the Department of Special Education and half through the Department of Psychology (Roll-Pettersson, Ek & Ramnerö, 2010). To date approximately 250 psychologists, special educators, social workers, educators and speech language pathologist employed by either habilitation centers or municaplities have taken these courses. A spinoff effect of the personal meetings between students from different organisations has in a few cases resulted in new types of inter-organisational collaborative partnerships and positions (Roll-Pettersson & Olsson (in progress).

Ethics

The explicit values of ABA center around the enhancement of socially relevant and culturally valued quality of life (Baer, Wolf & Risley, 1969). The targets for interventions are those behaviors that constitute barriers affecting the quality of life for individuals, families, or communities, including issues within families, relationships, social life, education, health, employment, leisure activities and relaxation (Cooper, Herron, & Heward, 2013).

There is nothing remarkable about the selection of these targets; they include the same goals and aspirations most people have for themselves and for their loved ones. The key issue is that unless the apposite behaviors occur, these goals and targets remain out

of reach. The focus of ABA is to help facilitate behavioral growth and skill development to enhance the quality of life. ABA operates within a natural science perspective and using the scientific method applied to individuals, it offers the necessary behavioral insights and technology to achieve the goals associated with agreed values.

Training in ABA also adheres to clearly defined ethical standards (BACB, 2014). Issues concerned with professional ethics, though, often extend beyond the actual practice of a science. For example, in relation to representation on review panels, a guiding principle in most professions is exemplified by this statement from another scientific body:

> As a general rule, in matters concerning physics, the Institute of Physics in Ireland would seek to have appropriately qualified physicists represented on any review panel which might be reporting on 'findings from physics'. (*personal communication*, Institute of Physics in Ireland, May,2012)

Similar concerns about professional competence are enshrined in ethical standards of other professional bodies such as Social Work, Psychology, Speech and Language Therapy, Occupational Therapy, all of which usually have an input in policy and practice decisions in relation to autism treatment.

Unfortunately, this ethical imperative has been routinely flouted when it comes to the science and profession of Applied Behavior Analysis (see ethical guidelines from BACB, 2014). For example, in both Northern Ireland and in the Republic of Ireland to-date, none of the huge numbers of the autism reports or strategy documents have included any professionally qualified representative of ABA (Keenan, 2014;

McCormack, 2014; Behaviour Analysis in Ireland, 2013). Consequently, due to the Dunning-Kruger effect, misinformation and the associated caricatures of ABA have formed the basis of government strategies and policies (Dillenburger, McKerr, & Jordan, 2014).

Category Mistake & Evidence Base

A common mistake is the confusion of ABA (the science) with methods derived from ABA. When conducting reviews on the effectiveness of particular methods or procedures, it is important that there is clarity on the distinction between procedures or commercial products and the science from which they have been derived. This is a complicated issue for those not adequately trained in the science, and the ethical guidelines mentioned above are particularly relevant here. Figure 3 was designed to help demonstrate the category mistake (Chiesa, 2005).

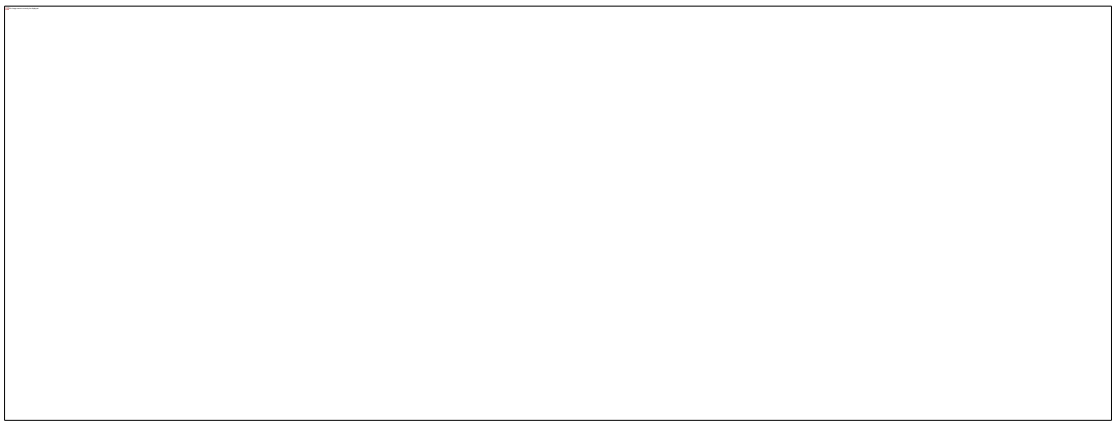

Figure 3. A classic category mistake.

> **Left-hand panel:** Applied Behavior Analysis (ABA) is wrongly put on the same 'shelf' as a range of discrete methods, such as Positive Behavior Support (PBS), Verbal Behavior Approach (VBA), Lovaas, TEACCH, Picture Exchange Communication System (PECS); Early Intensive Behavioral Intervention (EIBI)

and Early Start Denver Model (ESDM) could also be added to replace the "?" on the bottom shelf. This arrangement is inaccurate because ABA is the name of the higher-level category from which these methods are derived.

Right-hand panel: As a corollary to the mistake on the left-hand panel, 'Fruit' is wrongly placed on the same 'shelf' as apples, oranges, and pears etc. This is inaccurate because fruit is the name of the higher-level category to which the other items belong.

When ABA is correctly described, discussions about the evidence for ABA take on a different dimension. Take, for example, the argument that there are no Randomised Control Trials (RCTs) of ABA and therefore ABA cannot be recommended. The National Institute for Clinical Excellence (NICE), in their response to the consultation for guidelines for the management of children with autism concluded the following: 'In the review of evidence, the Guideline Development Group found no evidence to support ABA, and therefore could not make a recommendation about it' (NICE, 2013). Unfortunately, there was not a single Board Certified Behavior Analyst on the NICE team who could have corrected this conclusion and NICE ignored protestations to the contrary! Certainly it makes sense to assess treatment packages that make claims as to their effectiveness (Smith, 2013), but it is disingenuous to obfuscate the distinction between treatment packages and the science from which these packages have been developed.

If the same category mistake were to be made with regards to other disciplines, we would end up with the following argument: There are no RCTs to justify the use of

Speech and Language Therapy, Medicine, Occupational Therapy, or Clinical Psychology. Clearly, RCTs are not appropriate for the assessment of whole disciplines (Keenan & Dillenburger, 2011) and it would be a mistake to conclude that because there are no RCTs these disciplines should not be used. Similarly, it is a mistake to suggest that Speech and Language Therapy, Occupational Therapy, Medicine, or Clinical Psychology are each discrete treatment. Yet, politicians are frequently informed that ABA represents a 'one-fits-all' approach (Dillenburger, Röttgers, Dounavi et al., 2014), and they therefore conclude that because each child with autism is different ABA cannot be recommended (NICE, 2013).

Contrast this conclusion with the practice of the science as discussed with respect to Figure 1. It really is a very serious state of affairs when professionals misinform policy makers about a science; that's why adherence to normal ethical standards is so important. The misinformation on ABA has been so pervasive in N. Ireland, that a previous Minister of Education even described ABA as a 'commercial product' (Ruane, 2009).

In conclusion, it is now possible to diagnose autism reliably much earlier and prevalence is estimated to be 2% of children (CDC, 2013; DHSSPS, 2014). As these children grow up, it is important that debates based on misinformation do not waste valuable resources that should be used to support individuals with ASD. The mischaracterization of a science that can effectively address the pertinent issues has serious consequences for parents and their children. Why shouldn't parents and professionals be trained according to the model outlined in Figure 1? This is the question that parents have been putting to governments in their own countries

(ABA4all, 2014; Unumb, 2013; Medicare for Autism Now, 2014). ABA is the basis of evidence-based practice par excellence and the outcomes achieved by skilled professionals explain the proliferation of requests to avail of this science by parents worldwide. Unfortunately, straw man arguments are obscuring the true nature of ABA and are thus preventing the light from a science of behavior reaching those who might benefit from its findings.

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