

## HTA-Report | Summary

# Behavioural and skill-based early interventions in children with autism spectrum disorders

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## Introduction

Autism spectrum disorders (ASD) comprise typical or infantile autism (Kanner syndrome), Asperger's disorder and atypical autism or pervasive developmental disorder - not otherwise specified. The syndrome is characterized by deficits in (1) verbal and nonverbal communication, (2) reciprocal social interaction, and (3) repetitive patterns of behaviour, interests and activities.

In the last years epidemiological studies have shown increased prevalence rates; however, it is not clear if this is due to methodological problems of studies, the change of diagnostic criteria, or if it reflects true rising prevalence. People with autism often require care and support over longer time periods, sometimes life-long. Children with autism attend all available kinds of nursing and school classes with special forms of instruction and specialized classes in smaller groups are implemented to meet the special needs of the children. However, adequate support with respect to the special needs of the disorder is not always available in Germany. Adult persons with autism receive care in different settings, institutions and social services; only some of these are adequately prepared to deal with their specific needs.

For autism, pharmacologic as well as psychosocial treatment options are available. Some medications can improve behavioural or emotional aspects of the disorder. However, there is no evidence that the course of the disorder can be influenced. Most interventions are psychosocial interventions and aim at improving child development and behaviour and strengthen or shape familial and social bindings and contacts. Most psychosocial interventions are based on learning theory and behaviour therapy and take into account the specific deficits in perception, emotional reactions, social interaction and communication.

In Germany, these comprehensive models are not widely evaluated and implemented. There are strong expectations with regard to these early behavioural interventions developed in the USA as early studies showed that a significant portion of treated children reached cognitive improvements that made them undistinguishable from normal peers and could attend normal classes. However, these early studies have been criticised because of methodological problems and selection effects. Thus newer studies have to be evaluated in order to get information on which early interventions are worthwhile being implemented in Germany and what are the active components.

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## Research questions

The evaluation of early intervention programmes in autism is a great challenge due to the nature of the disorder and methodological problems. Currently there are no uniform evaluation standards. Study outcome parameters in autism research should aim at the core symptoms and deficits including development, communication, social interaction, language and behaviour as well as questions of sleep, aggression, intelligence, quality of life and objective measures as normal school attendance rates and institutionalization rates. The objective of this health technology assessment (HTA) is to perform an evaluation of the clinical effectiveness and safety of behavioural or skills-based early interventions in autism among each other and against routine treatment, and to look at active ingredients like type and intensity of treatment.

The economic part aims at estimating the cost-effectiveness and cost consequences of different behavioural or skills-based early interventions in autism.

Furthermore some ethical, legal and social aspects are discussed.

## Methods

The relevant literature for the topic is identified through a systematic electronic review, a hand-search, and the contacting of appropriate institutions. However, the expert survey does not claim completeness.

Controlled studies published since 2000 in English or German with children until the age of twelve years having a diagnosis of autism according to internationally accepted criteria (Diagnostic and statistical manual of mental disorders (DSM) or International classification of diseases (ICD) criteria) are included. The minimum participant number must be ten per intervention group. The study must evaluate behavioural or social skills interventions specifically developed for autism. A behavioural or social skills intervention is defined as an intervention aiming to improve the behaviour and/or functional skills or child development using strategies of behaviour therapy or social skills training. Outcome parameters must be assessed at least six months or later after the beginning of the study. No restrictions are defined with regard to the endpoints under investigation. All studies are selected independently by two researchers according to predefined inclusion and exclusion criteria.

## Results

Using a list of search terms, a total of 2,281 clinical studies (999 publications or primary studies, 1,251 publications of reviews, and 30 publications of HTA), 235 economic and 135 ethical/legal studies are identified. Following a review of the abstracts, 102 clinical and 52 economic publications are marked as being potentially relevant. Of the 102 clinical studies, a total of 15 fulfil the predefined inclusion criteria and are included in the present HTA.

These 15 publications are based on 14 studies, eight are randomized controlled trials (RCT), six are non-randomized controlled trials. Only one health economic study is included. Three evidence-based practice guidelines are reported. Six studies are conducted in the USA, five in Great Britain and one each in Israel, Australia and Norway. No study was performed in Germany.

Most studies evaluate early interventions based upon the Lovaas model (Early intensive behavioural treatment (EIBT), Applied behavioural analysis (ABA)). Other evaluate pragmatic interventions or interventions based on other theories like specific parent interventions, Responsive education and prelinguistic milieu teaching (RPMT), joint attention und symbolic play, and Picture exchange communication system (PECS). The evaluated interventions and control interventions differ considerably. The latter include treatment as usual,

eclectic treatment using a mixture of elements, low-frequency treatment and waiting lists.

Based on a systematic evaluation of primary studies, reviews and HTA reports, behaviour analytic interventions referring to the Lovaas model remain the most empirically evaluated early interventions for children with autism. In most studies children with a higher initial intelligence quotient (IQ) had a better outcome than those with lower IQ. The effectiveness varies strongly with the type of the control intervention. Studies suggest that preschool children in behavioural interventions with a frequency of at least 20 hours per week with autism can achieve improvements in cognitive and functional domains (expressive and receptive language and communication). It is not clear which is the minimum duration of effective interventions, and which active components are necessary. In addition there is no solid evidence of a superiority of very early interventions. On the basis of the selected studies no solid statements are possible with regard to factors responsible for the effectiveness of programs according to the Lovaas model. On the other hand, a systematic parent training seems to be superior to treatment as usual with regard to communication improvement.

There was no high quality evidence for other comprehensive early interventions. There was weak evidence that improvements in social communication and language observed in studies with PECS or RPMT is effectively transferred into childrens' daily life.

The identified health economic study is not suitable to evaluate the cost-effectiveness or cost consequences of early interventions in autism. In this study costs for early intervention programmes (according to the Lovaas model) of between GBP 15,000 and 30,000 were reported. However, the study had severe methodological limitations like lacking reference times. Effectiveness measures were not combined with cost estimates. Thus no statement is possible with regard to resource allocation. In a descriptive study a value of more than USD 60,000 for a behavioural early intervention programme is given. Valid statements for the German context are not possible.

No publications concerning legal, ethical or social aspects were identified. The financial situation of persons with autisms and their families will be improved through the implementation of the "Pflege-Weiterentwicklungsgesetz" (Pf-WG). Further questions address the organisation of care and the legal representation of autistic patients. Ethical questions arise mainly in the context of the equal supply of care to each individual patient in all regions of the country and the situation of the caregivers. Another point is the situation of the caregivers in a home setting, especially as they get older.

## Discussion

There are only a few studies with qualitatively high methodology evaluating early interventions in autism. Most studies have a short duration with no blinded outcome assessment. Manual fidelity has not always been assessed. In most studies standardized outcome parameters are used. However, for example the Wechsler intelligence scales used in many studies may not be optimal in autism research.

The lack of high quality comparative studies does not allow answering questions of comparative effectiveness of early interventions in autism. It can be concluded that interventions referring to the Lovaas model remain the most empirically evaluated early interventions in autism. This seems to be especially true when they are run clinic-based. A systematic parent training seems to be superior to treatment as usual with regard to communication improvement.

As well for clinical and health economic studies there is a substantial problem of generalizability into the German context. Clinical studies show that effect sizes

differ according to the type of the control intervention. Therefore further studies in Germany may be desirable.

There is evidence that intervention programmes including parents are of utmost importance. Parents should be trained as co-therapists and should know the relevant techniques. However, early intervention programmes should be adjusted to the families' needs. Interventions seem to be successful when they support families and help them to cope with and communicate adequately with their children. For the children it is important to be in close contact with peers at the same age.

Early interventions should focus on specific core elements like joint attention, expressive language and language comprehension, imitation and social interaction. It seems not appropriate to take into consideration all relevant aspects of childrens' daily life at the same time. A manual-based approach seems to have advantages compared to eclectic programmes with a mixture of different elements. There should be room for an individualized approach.

The identified economic study is not suitable to evaluate the cost-effectiveness or cost consequences of early interventions.

Ethical considerations for patients with autism focus on the autonomy of subjects, especially with respect to informed consent, while participating in studies. Other questions concern the equal accessibility of possibilities for treatment and questions that arise in the context of different treatment options.

The legal situation in Germany has changed just recently. A law, called Pf-WG, is intended to improve not only the financial situation of but also the support for patients and usual care givers. Another legal question concerns the legal capacity respectively the legal representation of people with autism. Depending on the severity of the illness, people with autism might not have the capacity to legally represent themselves and therefore cannot for example sign binding contracts. In this case a legal guardian (for young adults usually the parents) has to be assigned. Furthermore people with autism will probably also lack their capacity for delicts. Therefore they cannot be held liable for their acts. If a person with autism causes damages, it is possible, that the victims will end up without any compensation. Ethical questions are discussed with respect to an equal access to all existing health care options. This is especially the case in view of the home setting that is usually applicable in Germany by the respective families. Another concern in this context is the care burden for the caregivers, particularly as they get older.

## Conclusion

Based on the available studies there is no sufficient evidence for any of the evaluated early intervention programmes. Studies suggest that preschool children with autism in behavioural intervention programmes with a frequency of at least 20 hours per week can achieve improvements in cognitive and functional domains. There is no evidence that in a substantial portion of the children a normal development can be achieved by early interventions. In the studies with the best outcomes, for up to half of the included children an acceleration of the development could be achieved so that they approached the values of their normal peers. In other studies only modest improvements could be achieved compared to treatment as usual. Research evidence suggests that the core symptoms of autism are amenable to early treatment. Most research evidence is available for ABA. However, effect sizes depended on the control interventions with studies with higher intense control interventions having lower effect sizes. A minimal necessary intensity of

interventions to achieve positive outcomes cannot be derived from literature. There are no valid statements possible as to cost-effectiveness or cost consequences of these interventions.