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Notat om brugen af hjælpetrænere i hjemmebaseret, adfærdsanalytisk intervention (ABA) for børn med autisme

Applied Behavior Analysis (ABA) er en manualiseret og evidensbaseret metode til træning og læring af børn og unge med autisme. Notatet er skrevet med henblik på at belyse, i hvilket omfang, i hvilken form og med hvilke formål der anvendes hjælpere i hjemmebaseret, adfærdsanalytisk intervention til børn med autisme.

Notatet er baseret på en gennemgang af tre typer af skriftlige kilder

- manualer for adfærdsanalytisk intervention til børn med autisme
- lærebøger om adfærdsanalytisk intervention
- effektundersøgelser og familieundersøgelser af adfærdsanalytisk intervention

Resumé

Den gennemgåede litteratur om adfærdsanalytisk intervention til børn med autisme viser, at hjælpetrænere er en integreret og nødvendig del af metoden når denne praktiseres i barnets hjem. I de tre typer af litteratur, der er gennemgået i notatet, bliver træningen i alle tilfælde varetaget af et team bestående af forældre, ansatte hjælpere og evt. også af familiemedlemmer eller andre frivillige hjælpere.

Manualer til gennemførelse af ABA-træning af børn med autisme gennemgår de generelle principper for ABA-træning, organiseringen af træningen samt giver anvisninger på konkrete øvelser, programmer og udviklingsmål for træningen. I manualerne om hjemmebaseret ABA anvises i alle tilfælde, at træningen organiseres i et team bestående af forældre og hjælpetrænere. Det sker af følgende grunde:

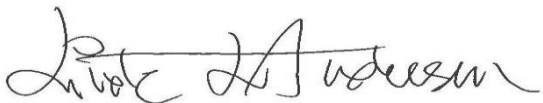
- a) generalisering af færdigheder – dvs. barnets evne til at mestre opgaver i forhold til forskellige voksne, i forhold til forskellige børn, i forskellige situationer og med forskellige materialer;
- b) indlæring af relationsskift – dvs. adressering af de problemer, som børn med autisme meget ofte har i overgange mellem forskellige situationer og forskellige personer samt de problemer, som børn med autisme typisk har i forhold til flere personer – fx gruppesammenhænge;
- c) aflastning af forældrene i træningsindsatsen – dvs. varetagelse af en del af træningsindsatsen eftersom ABA-træning ikke kun er intensiv for barnet med autisme, men også for de personer, der træner barnet. Det er derfor nødvendigt, at man er flere personer, der kan skiftes, for at træningen kan udføres med den tilstrækkelige kvalitet og energi;
- d) etablering af et team omkring barnet – dvs. en gruppe af personer, der samarbejder omkring barnets træning og som i fællesskab på møder med eller uden en ABA-

supervisor kan diskutere og træffe beslutninger om programmets videre udvikling og om tilpasning af øvelserne til barnets aktuelle behov.

Disse begrundelser for at anvende hjælpere i hjemmetræningen understøttes af effektforskningen og familieforskningen om ABA-metoden. I alle effektstudier af hjemmetræning efter denne metode anvendes hjælpere og interventionen organiseres i et team.

Gennemgangen af lærebøger om adfærdsanalytisk intervention giver en teoretisk forståelse for, hvorfor interventionen skal udføres af et team af forældre, fagfolk og hjælpere: børn med autisme kan i mange tilfælde ikke selv generalisere indlærte færdigheder til andre personer, hvorfor der må tilrettelægges en systematisk oplæring (kaldet stimulus-generalisering), der involverer flere personer, flere steder og med forskellige materialer. Stimulus-generalisering mellem personer forudsætter, at der i barnets team er andre voksne end forældrene – hjælpetrænere – der kan generalisere barnets færdigheder, som mestrer metoden og som systematisk kan gennemføre denne generalisering.

Litteraturgennemgang er gengivet på de følgende sider.



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Litteraturgennemgang

Indledning

ABA er en engelsk forkortelse for Applied Behavior Analysis – anvendt adfærdsanalyse. Adfærdsanalytisk træning eller intervention til børn med autisme og andre udviklingsforstyrrelser er et resultat af et 50-årigt forsknings- og udviklingsarbejde, som har fundet sted i et samarbejde mellem forskere fra psykologiske universitetsinstitutter og praktikere fra pædagogiske tilbud til børn med autisme. De første videnskabelige forsøg med ABA-træning til børn med autisme stammer fra begyndelsen af 1960'erne, hvor universitetspsykologer samarbejdede med statshospitaler og andre døgninstitutioner, hvor mange børn med autisme dengang var placeret. Siden er udviklingsarbejdet blevet flyttet til børnenes hjem, deres daginstitutioner og skoler.

I begyndelsen rettede interventionen sig primært imod enkelte adfærdsformer og havde især til formål at begrænse uhensigtsmæssig adfærd. Siden er metoden blevet helhedsorienteret og lægger i stigende grad vægt på læring af de former for adfærd, der er hæmmet hos børn med autisme. I 1981 udkom den første manual til træning af børn med autisme efter ABA-metoden, og samtidig igangsattes forskning i metodens effekter på børns kognition, sociale adfærd, kommunikation og autistiske symptomer. Metoden vurderes i dag til at være veldokumenteret i en lang række gruppebaserede og kontrollerede effektstudier. I den samme periode har mere end 250 universiteter oprettet bachelor, master og ph.d-programmer i anvendt adfærdsanalyse, og der er hertil skrevet et betydeligt antal lærebøger i anvendt adfærdsanalyse.

Manualer for adfærdsanalytisk intervention til børn med autisme

Manualer er lære- og håndbøger i helhedsorienterede, autismspecifikke adfærdsanalytiske interventioner. Disse bøger indeholder anvisninger på interventionens organisering, på trænings- og undervisningsteknikker og forslag til programmer og øvelser. Manualerne er udgivet af universitetsklinikker eller ABA-centre, og navngives efter disse. Der er offentliggjort 14 manualer for træning og oplæring af børn med autisme:

- UCLA Young Autism Project, University of California Los Angeles (O. Ivar Lovaas, 2002; O. Ivar Lovaas et al., 1981)
- Institute for Child Development, State University of New York, Binghamton (Romanczyk, Lockshin, & Matey, 1995)
- Alpine Learning Group, New Jersey (Maurice, Green, & Foxx, 2001; Maurice, Green, & Luce, 1996)
- The Claremont Autism Center, Claremont Graduate University, California (Charlop-Christy & Kelso, 1997)
- Behavior Analysts, California (Sundberg & Partington, 1998)
- Autism Partnership (R. Leaf & McEachin, 1999; Ronald Leaf, Taubman, & McEachin, 2008)
- LEAP (Learning Experiences and Alternative Program for Preschoolers and Their Parents), University of Colorado at Denver (P.S. Strain, & LEAP Outreach Program, 2003).
- STAR - Strategies for Teaching Based on Autism Research, Portland State University (Arick, J. R., 2004).
- Koegel Autism Center, University of California Santa Barbara (Koegel & Koegel, 2005)
- Pyramid Educational Consultants, Delaware (Bondy & Sulzer-Azaroff, 2007)

- Early Start Denver Model, M.I.N.D. Institute, University of California Davis Medical Center (Rogers & Dawson, 2009)
- Reciprocal Imitation Training, Michigan State University (Ingersoll, B., & Dvortcsak, A., 2010).
- The New England Center for Children (The New England Center for Children, 2013).
- Knapp Center for Childhood Development (Knapp, J., & Turnbull, C., 2014)

Antallet af manualer afspejler metodens udvikling. Nye forskningsresultater nødvendiggør revision af tidligere manualer og samtidig er der sket en differentiering af metoden, således at der nu er særlige manualer til ultratidlig intervention til børn i vuggestuealderen, særlige manualer til træning af kommunikation, af gensidig interaktion og af kerneudviklingsområder hos børn med autisme.

Oprindeligt blev ABA-intervention udelukkende udført af fagfolk på universitetsklinikker, i skolesystemet eller i specialinstitutioner. Den tidlige effektforskning dokumenterede dog, at en stor procentdel af behandlede børn med autisme efterfølgende gradvist mistede deres tillærte færdigheder, fordi færdighederne ikke blev vedligeholdt i børnenes naturlige omgivelser – primært i deres hjem. Derfor eksperimenteredes med en aktiv inddragelse og uddannelse af forældre i ABA-metoden, således at de kunne videreføre og opretholde øvelser og børnenes kunnen i deres dagligdag (Ole Ivar Lovaas, 1977; O. Ivar Lovaas, Koegel, Simmons, & Long, 1973).. Efterhånden som efterspørgslen efter adfærdsanalytisk intervention voksede og ikke længere kunne opfyldes af særligt uddannede fagfolk, udvikledes egentlige hjemmebaserede interventioner.

De hjemmebaserede interventioner er karakteriseret ved

- at forældrene påtager sig behandlingsansvaret
- at der i hjemmet etableres et team af trænere – herunder forældre og andre familiemedlemmer
- at en af forældrene fungerer som teamleder
- at hele teamet modtager regelmæssig live supervision fra en kvalificeret adfærdsanalytiker

Af de 14 manualer de 5 træning i hjemmet; de resterende beskriver ABA-metoden praktiseret af professionelle.

Manual fra UCLA Young Autism Project, University of California Los Angeles

Teaching developmentally disabled children er den først udkomne manual – udgivet i 1981 (O. Ivar Lovaas et al., 1981). Bogen er skrevet til forældre, der træner deres barn i hjemmet. Ifølge bogen bør hjemmetræning organiseres i et team, eftersom et team omkring barnet kan forhindre udbændthed hos forældre, der træner deres barn:

Be prepared for hard work; developmentally disabled persons often have to be taught everything in the smallest detail. Many do not respond in the beginning, and you have to be extremely patient. Get some help to prevent burn-out. Hire assistants and form a "teaching team." The ideal teaching team probably numbers between four and eight people, each working about four to eight hours per week. If your child gets from 20 to 60 hours of one-on-one teaching per week, he will probably get as much instruction as he can handle. It is critical that teaching be carried out everywhere - at home, at school, as many hours a day as possible. Everybody has to teach, and everybody has to teach in a consistent manner, at least in the beginning. (O. Ivar Lovaas et al., 1981, s. 4).

Bogen beskriver en arbejdsdeling mellem forældre og hjælpere, hvor den ene forælder fungerer som teamleder, der har ansvaret for oplæring og organisering af træningen:

(Assistants) learn what you have learned from the program, and then they do most of the work with your child; you are the expert; you are the consultant. Assistants can be parents, teachers, normal sibling, or high school and college students.

Expect your assistants to stay on the job for 6 months to a couple of years; they come and go, you have to stay. If you have a large group of assistants, assign specific responsibilities (and authorities) to different persons. For example, one person becomes the expert at constructing programs for building some aspect of language, another person leads the group in building play skills, one works on dressing and self-help, one is the liaison between the parents and the teacher, and so on. Each person works in every program, but each program has only one person in charge. You are in charge of the entire program. (O. Ivar Lovaas et al., 1981, s. 4)

Denne manual understreger betydningen af, at man holder regelmæssige team-møder, hvor der lægges planer for den kommende tid, og hvor øvelser demonstreres:

Have a weekly "staff meeting" for 1 hour to discuss what has been done in the past week and to lay plans for the following week. Each person should work with the child, in front of everyone else during staff meetings to get feedback, positive or negative, regarding teaching methods. Such weekly supervision is important. During the first 2 or 3 months, it perhaps is best to have assistants work in pairs so that they can better identify each other's mistakes and note superior procedures. If a team member doesn't agree to this and feels so "senior" and experienced that he wants to do it his own way, or so sensitive that he can't stand criticism, then let that person go before he hurts your program. (O. Ivar Lovaas et al., 1981, s. 4).

Manual fra Alpine Learning Group, New Jersey

Den mest udfoldede beskrivelse af hjælpetrænere og deres rolle i hjemmebaserede ABA-tilbud findes i manualen *Behavioral intervention for young children with autism: A manual for parents and professionals* (Maurice et al., 1996). Bogen har et særligt fokus på hjemmebaserede interventioner, og indeholder et helt kapitel om 'recruiting, selecting, and training teaching assistants'. (s. 231-248).

Indledningsvis præciseres, at hjælpetrænere er afgørende for hjemmebaserede træningsforløb til børn med autisme:

Teaching assistants (TAs) are the people who do most of the work in intensive behavioral programs. They may be referred to as teachers, teaching assistants, or therapists. Regardless of what we call them, their role is critical in the success of home-based behavioral, early intervention programs. They are, in a very real sense, the backbone of the program.

Begrundelserne for brugen af hjælpetrænere er dels, at de fungerer som assistenter for forældrene og dels at de sikrer den nødvendige generalisering af tillærte færdigheder:

Teaching assistants are essential to home-based intensive behavioral programming. Parents are rarely able to do the job alone. The energy required of parents to meet the

non-intervention needs of a child with autism (as well as the needs of other children and family members) may leave little or no energy for active teaching. (...)

Remaining fresh so as to be effective in essential parental roles requires time away from the child. It takes time to coordinate intervention activities and personnel. From a technical perspective, using several TAs allows newly acquired skills to be more readily generalized to different trainers. In some families, there may simply be no one with the time or capacity to provide intensive teaching. For these, and many more reasons, TAs are necessary.

De kvalifikationer, som en hjælpetræner skal have, beskrives på følgende måde:

What should you expect these TAs to do? (...) You will want someone to carry out the intervention activities. This initially means someone to run discrete trials, take data on the response to each trial and reinforce good work according to the established program. Your TA must be able to withhold reinforcement and re-present trials as specified in the program. (...) TAs must be capable of understanding the program objectives and should be committed to helping your child make rapid progress. In order to be effective, they must be able to relate to your child and find joy in his or her progress. They must do this while insisting that the child comply with the program and earn reinforcement only for correct (or improved) responses.

In short, you will want someone who is a teacher of your child. This teacher will be expected to carry out a systematic instructional sequence planned by a specialist. He will be expected to act independently, manage your child when necessary, interpret the program in light of your child's progress during the session, and reinforce your child as enthusiastically and effectively as possible, contingent on good performance. You will treat him like a teacher, and he should act like a teacher.

Forældrenes rolle som teamledere beskrives også, og indeholder bl.a. forberedelse af nye øvelser, fremskaffelse eller køb af træningsmaterialer samt ledelse af træningsprogrammet.

Parents incur several important responsibilities in this relationship. Among these are maintaining the role expectations for the TA, providing the necessary program supports, and providing feedback and positive reinforcement. Once you have established the teaching and training expectations, you should stick with them. (...)

The TA will count on you to coordinate the learning activities and provide the needed materials. Unless you specifically pay TAs to do so, do not expect them to gather the materials for teaching. As parents, you will want to keep these items for the use of all the TAs. It is not appropriate to ask the TA to plan or supervise other TAs in the program. This is the responsibility of a professional with training in behavior analysis who will be working with you to create and guide the program.

Parents must provide many forms of support for the TAs. Parents will typically incur the costs of initial training. They pay for the professional consultation and program monitoring essential to keep the program on track, which often includes some direct consultation for the TAs. This consultation should be responsive to any special concerns or questions they may have. Apart from this, parents must provide feedback on session, progress and keep the TA apprised of progress achieved by other TAs. Your feedback must be accurate and honest to be useful. If you, as a parent, see that

the TA is making an error or is off-track, you must provide corrective feedback in a supportive manner, telling them just what to do to correct the performance deficit.

Manual fra Behavior Analysts, California

Protokollen fra ABA-centeret *Behavior Analysts* beskriver i et afsnit de typiske elementer i intensive, hjemmebaserede ABA-forløb - inklusiv brugen af hjælpere, som her kaldes for 'instructional staff' eller 'instructors' (Sundberg & Partington, 1998):

There are several major components of an intensive home-based educational program. In these programs, services are often provided on a one student to one instructor basis. The services are typically provided for approximately 25 to 40 hours per week, with the majority of the instruction being provided in a data-based, discrete trial learning format. The instructional personnel are often the child's parents and several college students who are interested in working with special education students, and who have received preservice training on the instructional methodology and program for a particular child. The instructional program is designed and monitored by a consultant who has had advanced training in the instructional methods being utilized. Team meetings are scheduled on a regular basis (e.g. weekly) for all of the instructional team members to review the child's performance and to coordinate changes in the instructional program. (s. 275f)

I samme bog er der desuden en beskrivelse af forældrenes rolle som teamleder og de arbejdsopgaver og problemer denne funktion afstedkommer:

The assembly and maintenance of instructional staff is often a formidable task that requires a major parental commitment. Parents are often the ultimate team leaders for this type of program and frequently spend considerable amounts of time recruiting and scheduling staff to provide the services. The scheduling includes both the day-to-day delivery of services (e.g., when staff are sick, changes in the staffs' schedules), and the training of new staff when previously trained staff are no longer able to work with the child. The coordination of the instructors, both logistically and with regards to the continuing supervision and training is reported by many parents to be a "full-time job." (s. 276)

Manual fra Autism Partnership

Manualen fra Autism Partnership (R. Leaf & McEachin, 1999) understreger arbejdsbyrden ved at være forældre til et barn med autisme og at træne med barnet i hjemmet. Derfor anbefaler bogen, at man etablerer et team bestående af hjælpere – her kaldet 'hired therapists' – og at forældrenes rolle primært er generalisering af indlærte færdigheder i naturlige omgivelser:

Parents often provide direct therapy to their child. However, as parents know all too well, living with an autistic child takes a big emotional toll and coordinating the treatment team is a big job. Therefore, whenever possible, it is recommended to use hired therapists to do most of the intensive work. This allows parents to have some respite and the remaining time spent with their child can be more enjoyable and productive. Parents can use the child's time that is not spent in intensive programming to develop play, social and self-help skills. Outings to the park, grocery shopping, mailing a letter and visits to a relative's home are opportunities to generalize skills and work on improving behaviour. Similarly, bath time, dinner, getting dressed, and feeding the cat are just a few examples of everyday routines that serve as opportunities

for teaching. In this way, the child's entire day becomes part of the therapy process and the parents become an integral part of the team. It is important to involve the child in the daily routine of living, therefore pushing against further isolation. (R. Leaf & McEachin, 1999, s. 10f)

Manual til Early Start Denver Model, M.I.N.D. Institute, University of California Davis Medical Center Early Start Denver Model, som oprindeligt er udviklet ved University of Colorado i Denver, men som nu videreudvikles ved *M.I.N.D. Institute* i Davis, Californien, forkortes ESDM (Rogers & Dawson, 2009). I denne manual, som især retter sig imod børn med autismespektrumdiagnoser eller mistanke om autisme i vuggestuealderen, understreges betydningen af hjælpere i hjemmetræningen og etableringen af et behandlingsteam omkring barnet. Hjælpere betegnes her 'paraprofessionals':

Paraprofessionals often play major roles in the delivery of care in group programs and intensive home interventions. They also have an important role on the team. Regardless of the type of ESDM delivery being used (center based, inclusive preschool, parent coaching, or intensive home delivery), an interdisciplinary treatment team is necessary for developing and monitoring appropriate delivery of the ESDM. (...) People on an autism intervention team may lack formal training in infant mental health, but the concepts are crucial, and a family focus is considered fundamental to successful infant-toddler interventions. The necessity of a family focus is represented in the *Individuals with Disabilities Act* (IDEA, 1991), which requires of participating states that education for children under 3 years of age be organized and delivered according to an individualized family service plan (IFSP) which includes home visits, training, and counselling services to the family in addition to direct services for the child. (Rogers & Dawson, 2009, s. 40f)

Lærebøger om adfærdsanalytisk intervention i forhold til børn med autisme

Anvendt adfærdsanalyse som pædagogisk intervention er baseret på såkaldt analog læring. 'Analog' betyder i denne sammenhæng tilsvarende men ikke identisk – jf. analogi, som betyder overensstemmelse eller lighed. Analog læring betyder, at der tilrettelægges en læringsituation, som er en model af naturligt forekommende situationer eller adfærdsformer, men som ikke er identisk med disse. Analog læring anvendes ikke kun i adfærdsanalytisk intervention for børn med autisme, men kendes fra en lang række andre undervisnings- og træningsformer.

Analog læring har en række fordele til forskel fra læring i naturlige situationer:

- som træner, lærer eller pædagog har man kontrol med de opgaver og andre stimuli, som barnet udsættes for;
- træningen kan tilrettelægges systematisk, progressivt og intensivt;
- træningen kan tilrettelægges trinvist, således at opgavernes gradvist ændres i forhold til barnets præstationer;
- det er let at følge træningens progression ved hjælp af data fra læringsituationen.

Selv om analog læring således kan være mere effektiv end læring i naturlige situationer, så rummer analog læring det problem, at det indlærte skal kunne anvendes uden for læringsituationen. Alle former for analog læring – herunder adfærdsanalytisk intervention – forudsætter således, at det indlærte generaliseres med andre personer og i andre situationer. Dvs. gøres anvendeligt uden for læringsrummet. Hos typisk udviklede børn kan man ofte gå ud fra, at barnet selv magter at overføre indlærte færdigheder til nye, ikke-trænede situationer, men fra autismeforskningen har man længe – siden 1960'erne – vidst, at personer med autisme i større eller mindre grad har problemer med selv

at generalisere deres adfærd til nye og ukendte situationer (O. Ivar Lovaas et al., 1973). Derfor har man i adfærdsanalytisk intervention indbygget elementer, der systematisk opbygger en generalisering, og man tester løbende barnets evne til at anvende indlærte færdigheder i forskellige situationer, med forskellige personer og med andre naturligt forekommende stimuli.

I den adfærdsanalytiske litteratur er generalisering defineret som

The occurrence of relevant behavior under different, nontraining conditions (i.e., across subjects, setting, people, behaviors, and/or time) without the scheduling of the same events in those conditions. Thus generalization may be claimed when no extratraining manipulations are needed for extratraining changes; or may be claimed when some extra manipulations are necessary, but their cost is clearly less than that of the direct intervention. Generalization will not be claimed when similar events are necessary for similar effects across conditions (Stokes & Baer, 1977, s. 350)

I nyere adfærdsanalytiske lærebøger anvendes begrebet generalisering ikke kun for evnen til at kunne overføre analogt indlærte færdigheder til naturligt forekommende situationer, men også for den læringsproces, der fører frem til dette resultat. Indlæring af generaliseringsfærdigheder er – i lighed med principperne for anvendt adfærdsanalyse – baseret på trinvis læring. Det vil sige, at man systematisk, gradvist og tilpasset barnets forudsætninger, trinvist introducerer såkaldte distraktorer, der gør det muligt langsomt at opøve evnen til at generalisere færdigheder, der er etableret i analoge situationer. I stedet for at generalisere fuldt ud vil man altså indlære generalisering trinvist ved at ændre på læringssituationen, således at denne med tiden tilnærmer sig naturligt forekommende situationer. Det gøres som regel ved at man i første omgang introducerer fremmede elementer i en analog situation – fx andre personer og andre materialer – og ved at man flytter træningen til andre lokaliteter. Næstsidste led i en træning af generalisering vil være støtte til, at barnet kan bruge sine færdigheder i naturlige situationer, hvorefter det testes om barnet kan udføre adfærden på egen hånd i naturlige situationer. Hvis det er tilfældet, opfattes adfærden som fuldt generaliseret; hvis det ikke er tilfældet; vil man gå tilbage til det senest mestrede trin og gentage procedurerne herfra.

I lærebøger skelnes mellem forskellige former for generalisering (Cooper, Heron, & Heward, 1990, s. 556ff):

- generalisering af materialer (stimulusgeneralisering)
- generalisering af personer (stimulusgeneralisering)
- generalisering af steder (stimulusgeneralisering)
- generalisering over tid (opretholdelse af adfærd)
- generalisering af relevant adfærd (responsgeneralisering)

Alle de nævnte former for generalisering med undtagelse af stimulusgeneralisering mellem personer kan gennemføres med en og samme træner. Generalisering mellem personer kan derimod kun indlæres hvis der er flere personer, der kan gennemføre træning og overførsel af færdigheder fra en person til andre personer. Stimulus-generalisering mellem personer forudsætter altså, at der i barnets omgivelser er andre voksne end de primære trænere, der kan generalisere barnets færdigheder; dvs. personer som kender og mestrer metoden og som systematisk kan gennemføre denne generalisering. Denne generalisering udføres fx af hjælpetrænere.

Forskningslitteraturens angivelser af interventionens organisering og brugen af hjælpere

Den relevante forskningslitteratur omfatter to typer af studier – dels effektstudier, hvor fokus er på børnenes udvikling og læring, og dels studier af hjemmetræningens indflydelse på familien, søskende og på forældre. Forskningslitteraturen om ABA-intervention er meget omfattende og her er kun gennemgået egentlige kontrollerede eller komparative gruppestudier. Forskningslitteraturen dokumenterer metodens positive og negative effekter på børnene, på børnenes familie og undersøger de faktorer, der bidrager til metodens effekter. Forskningslitteraturen beskriver normalt kun kortfattet den behandling eller intervention, som børnene har modtaget – herunder brugen af hjælpetrænere i hjemmet og teamorganisering.

Effektstudierne

Der er gennemført 64 gruppestudier af effekter af ABA-intervention til børn med autisme. Af disse omhandler de 19 hjemmebaserede tilbud (Anderson, Avery, DiPietro, Edwards, & et al., 1987; Beglinger & Smith, 2005; Bibby, Eikeseth, Martin, Mudford, & Reeves, 2002; Birnbrauer & Leach, 1993; Boyd & Corley, 2001; Cohen, Amerine-Dickens, & Smith, 2006; Dawson, G., 2010; DiPietro et al., 2002; Eikeseth, Hayward, Gale, Gitlesen, & Eldevik, 2008; Fava, L., 2011; D. Hayward, Eikeseth, Gale, & Morgan, 2008; Luiselli, Cannon, Ellis, & Sisson, 2000; Perry et al., 2008; Reed, Osborne, & Corness, 2007; Remington et al., 2007a; Sheinkopf & Siegel, 1998; Smith, Buch, & Gamby, 2000; Stoelb et al., 2004; Weiss, 1999). I de øvrige studier indgår forældretræning og -generalisering i varierende omfang, men hovedparten af interventionen er henlagt til center-baserede tilbud (dvs. professionel behandling leveret af universitetsklinikker og af privatpraktiserende supervisionscentre) eller til daginstitutioner og skoler.

I alle effektstudier af ABA-tilbud til børn med autisme i hjemmet er interventionen organiseret i et team og der indgår hjælpere. Der er imidlertid ikke foretaget eksperimenter, hvor man har sammenlignet intervention i hjemmet med og uden hjælpere eller med et forskelligt antal hjælpere. Derimod er der forsket i udvikling af hjælpetræneres kvalifikationer (Feldman & Matos, 2013; Leblanc, Ricciardi, & Luiselli, 2005; Quilty, 2007; Wood, Luiselli, & Harchik, 2007) og i betydningen af, at hjælpetrænere modtager kvalificeret supervision (Eikeseth, Hayward, Gale, Gitlesen, & Eldevik, 2008; Takeuchi, Kubota, & Yamamoto, 2002; Gibson, Grey, & Hastings, 2009).

Nogle eksempler kan belyse, hvordan effektstudier beskriver brugen af hjælpere og organiseringen i teams.

En engelsk oversigtsartikel om de britiske erfaringer beskriver de nøgleelementer i et tidligt, intensivt ABA-tilbud, der forskningsmæssigt har dokumenteret effekt: behandling i barnets naturlige omgivelser, intensitet, behandling baseret på principper fra anvendt adfærdsanalyse, personalets kvalifikationer, forældreinvolvering, evaluering af progressioner samt anvendelsen af forskningsresultater (D. W. Hayward, Gale, & Eikeseth, 2009). Det er vigtigt, at understrege, at denne artikel ikke omhandler et klinisk forsøg med særlige ressourcer, men derimod beskriver et standard-tilbud til børn med autisme, som trænes i hjemmet. Om de ressourcer, som anvendes i hjemmebaserede interventioner, hedder det:

Each child is assigned a programme consultant, providing 5 h per week of supervision, for 46 weeks per year. Supervision is distributed as follows: weekly 2 h team meeting; in home supervision during treatment sessions; school consultations; supervision to the senior tutor; meetings with parents; meetings with school staff and other professionals involved with the child; clinical administrative tasks related to the case, such as programming, task analysis and functional assessment.

A senior tutor is provided for each child for a minimum of 11 h per week, for 46 weeks of the year. The main duties of the senior tutor are to assist in running team meetings, provide one-to-one teaching and supervise tutors during one-to-one teaching, as well as to conduct related clinical administrative tasks.

Tutors are provided for 50 weeks of the year. Each child has two to five tutors. Tutors work a minimum of 10.5 h per week for each child they are assigned. This equates to two 3.5 h treatment sessions, a 2 h team meeting and 1.5 h of related administration. Parents are also scheduled to conduct one formal treatment session per week.

Hjælpetrænere betegnes i denne artikel og andre britiske forskningsrapporter som ‘tutors’. Sammen med forældrene udgør ‘tutors’ et team:

A weekly 2 h team meeting is conducted during which all team members, including parents, participate. During these meetings all team members work with the child on his/her current programmes. This enables the team, and in particular the programme consultant and senior tutor, to provide feedback on teaching procedures and progress. It also enables them to review the curriculum and interventions and revise them for the following week. Detailed notes are typed during the team meeting, based on the conclusions of all advice that was given and discussions that have been held. The team then follows this advice throughout the next week of teaching. The week is typically divided into 12 teaching sessions (including the team meeting and the parent session), each lasting approximately 3.5 h.

Ved nyansættelser sker der en oplæring af ‘tutors’:

Each new tutor is provided with a comprehensive information package including: company information; employment documents; code of practice and related policies; child protection policy; health and safety information; and ABA theory. Next they undertake the following training: half a day introduction where the content of the information package is reviewed; half-day seminar on basic theoretical principles; half-day seminar on advanced theoretical principles; up to four other seminars per year covering topics such as shadowing in school, generalisation, language training, and peer supervision. Each new tutor undertakes a practicum of 60 h during which time they are provided with hands on training, with one or two children. Tutors, senior tutors and programme consultants provide this training during treatment sessions and team meetings. The new tutor follows a checklist which specifies treatment skills to be learned; a colleague verifies mastery of each of these skills.

I de britiske hjemmetræninger er hjælpetrænerne ansat af supervisorscenteret, og ikke af forældrene. Det indebærer, at rekruttering og efteruddannelse kan få et mere professionelt præg end i de hjemmebaserede tilbud, hvor forældrene fungerer som arbejdsgivere for hjælpetrænere. Men i princippet er opgaverne de samme: der skal ske en rekruttering af egnede hjælpere, hjælpere indgår i barnets team og hele temaet modtager supervision.

De øvrige effektstudier gennemgås ikke i detaljer i dette notat, men der gengives nogle udvalgte citater vedr. interventionens organisering og brugen af hjælpetrænere

Tutors, and in some cases senior tutors, were recruited and managed by the families. Teams received training during programme consultant workshops. (D. Hayward et al., 2008)

All children in the intervention group received home-based early intensive behavioural intervention for 2 years. Trained tutors and parents delivered one-to-one teaching based on applied behavior analysis for 25.6 hrs per week on average (Remington et al., 2007b)

All the interventions were home-based ABA programs, and all offered mostly 1:1 teaching provided by a number of tutors under the guidance of an ABA Supervisor. (Reed et al., 2007)

Families also hired three to five potential therapists after advertising in local universities and colleges, newspapers, and unemployment offices. In some cases, therapists included family members and volunteers. (Bibby, Eikeseth, Martin, Mudford, & Reeves, 2001)

Children's parents recruited paraprofessional therapists and requested consultations on how to implement the UCLA treatment model in their homes. (...) Each child had 3–6 therapists (Smith et al., 2000)

Familiestudierne

Familiestudier er i denne sammenhæng undersøgelser af, hvordan intensive ABA-interventioner i barnets hjem påvirker familien: forældrenes og eventuelle søskendes velbefindende, stress-faktorer i familierne og de coping-strategier, som forældrene anvender. Familiestudier er hovedsagelig gennemført i England og Wales, hvor ABA-intervention hyppigst leveres i børnenes hjem til forskel fra andre lande, hvor ABA-intervention oftest organiseres i daginstitutioner, skoler eller på klinikker.

Der er gennemført 14 af de omtalte familiestudier (Grindle, Kovshoff, Hastings, & Remington, 2008; Richard P. Hastings, 2003; Richard P Hastings, 2005; Richard P. Hastings & Johnson, 2001; Richard P Hastings & Symes, 2002; Johnson & Hastings, 2002; Remington et al., 2007b; Trudgeon & Carr, 2007; Cebula, 2012; Estes et al., 2013; Goin-Kochel, Mackintosh, & Myers, 2009; Minjarez, Mercier, Williams, & Hardan, 2013; Schwichtenberg & Poehlmann, 2007; Symon, 2005) I alle studierne er ABA-interventionen organiseret i et team bestående af forældre samt et antal hjælpetrænere.

Som et eksempel på sådanne familiestudier kan man fremhæve en undersøgelse af Trudgeon & Carr (2007). Der er tale om en interviewundersøgelse blandt britiske forældre til børn med autisme i hjemmebaserede interventioner baseret på ABA-metoden. Børnene var mellem 4 og 9 år gamle og de havde modtaget træning i gennemsnit 2 år og den gennemsnitlige træningstid per uge var 32 timer. Interviews analyseres i fem temaer, og inden for alle temaer er der positive og negative konsekvenser: fx. er det belastende at hjemmet fungerer som arbejdsplads for trænere, men samtidig giver trænerne positiv støtte og kollektivitet omkring barnet. Og selv om det for forældrene er belastende at have ansvaret for træning, så er der samtidig positive psykologiske effekter af den indsigt og kontrol, som ansvaret giver. Stressfaktorer udlignes således af den støtte og indsigt, som ABA-behandlingen giver til familierne.

Om interventionens organisering i teams og med hjælpetrænere hedder det:

To establish a home-based EIBI programme, parents need to seek training and supervision, recruit a team of tutors to implement the intervention and equip this with

the relevant materials. Often, the family funds the intervention. (...) Several parents commented on the impact of having tutors working within their home, sometimes over long periods of time (...) Several parents felt that the constant presence of tutors in their home was an invasion of their family's privacy and managing the tutor team itself was also reported frequently as a source of anxiety. Nevertheless, many examples in the data indicate that tutors themselves also were regarded as a source of practical, emotional and social support. (Trudgeon & Carr 2007).

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