

ORIGINAL ARTICLE

Effectiveness of an information booklet on knowledge regarding care of children with autism

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ABSTRACT

Background: Despite the growing incidence of autism, there is very little awareness on this developmental disability affecting 3-4 children in every 1,000 born in India today. **Aim:** To prepare and evaluate the effectiveness of the information booklet on the level of knowledge of the caregivers in the care of child with autism.

Methods: Study was carried out by among 30 caregivers who were attending the inpatient and outpatient of child psychiatric centre, NIMHANS. A quasi experimental design with single group pretest - post test was used. A purposive sampling was used to select the caregivers. After the pre-test the caregivers were given the information booklet. The post-test was conducted on the seventh day of administration of the information booklet.

Results: Findings revealed that, there was significant difference in the pre and post test scores on various dimension of knowledge questionnaire demonstrated the effectiveness of the information booklet. It was found that the post-test knowledge score was having statistically significant association with three socio demographic variables.

Conclusion: According to this study information booklet can be used as one of the Information Education and Communication (IEC) materials to improve the knowledge of autism care givers.

Keywords: Information Booklet; Autism; Caregivers.

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Introduction:

The importance of childhood is well emphasized both in the ancient and modern literature. Children are the pillars of tomorrow. Children are vital to the nation's present and its future (WHO, 2003). In recent years, there has been an increased focus on issues that affect children and on improving their mental health (University Centre for Excellence in Developmental Disabilities Education, Research, 2007). Despite the growing incidence of autism, there is very little awareness on this developmental disability affecting 3-4 children in every 1,000 born in India today.

A study conducted by the Rehabilitation Council of India shows that the prevalence is 3-4 per 1,000 live births now in India which was 1 in 10,000 ten years ago. According to estimates, over 20 lakhs people are living with autism in India. World Health Organization puts the global prevalence at 1 in 500. However, no empirical studies have been done in India to establish these figures as yet. (University Centre for Excellence in Developmental Disabilities Education, Research, 2007)

A child diagnosed with autism may represent a constant source of stress on the family unit, as not only the caregivers affected, but also siblings and relationships among family members (Sanders JL, 1997). Parents of children with autism were more likely to score in the high aggravation range (55%) than parents of children with developmental problems other than autism (Schieve LA, Blumberg SJ, Rice C, Visser SN, 2009). Having to cope with the physical and emotional demands of caring for a child with autism poses a threat to the psychosocial wellbeing of parents and caregivers (Gray DE, 1992).

Caregivers of children with autism often experience helplessness; feelings of inadequacy and failure; anger; shock; guilt; frustration; and resentment (Jones, 1997). Also it was reported that mental health of children depends on the parenting. Raising a child with a disability, particularly a confounding disorder like autism, challenges parents in extraordinary ways (University Centre for Excellence in Developmental Disabilities Education, Research, 2007).

Need for the study:

With knowledge of autism we can avoid aggravating the situation for children with autism

(Wolff, 2004). The knowledge of the caregivers regarding the care of children with autism is highly important in rearing a child with autism. Knowledge of the caregivers is important in assessing the signs and symptoms, current condition, recurrence risk, carrying out the instructions and interventions prescribed by the physician, identifying the side effects of medications and handling the common behaviour problems at home.

But the knowledge of the caregivers regarding the care of children with autism is inadequate. This is evident by a study conducted by Whitelaw et al (2007) who aimed at describing the recurrence risk information currently being obtained by families affected by autism. They used methods of structured telephone interview of parents of 21 children who received a diagnosis of autism at Calvary Health Care, Australia between May 2005 and May 2006. Results reveal that only one of the 21 parents knew their true recurrence risk. Many overestimated their risk substantially, and in four cases this had led to a decision against increasing family size. Eleven parents said they had received no information about recurrence risk, and only one cited medical practitioners as a source of information about recurrence risk. It was concluded that current provision of information about recurrence risk to families affected by autism is inadequate.

Thus through education and knowledge people with autism can considerably improve their level of functioning and quality of life. The need for information for the caregivers on a variety of unexpected skills, and support, is immediate and urgent (Whitelaw C, Flett P, 2007).

Research has demonstrated that parents can be effective implementers of behavioural, social, and communication programmes with their children with autism. Researchers have studied the effects of including parents as direct service providers in their children's intervention process as a means of increasing the quantity and availability of intervention (Koegel LK, Koegel RL, Kellebrew D, 1996).

It is important to identify children with autism and begin appropriate interventions as soon as possible since such early intervention may help

speed the child's overall development, reduce inappropriate behaviours, and lead to better long-term functional outcomes (McConachie H, 2007). Parent education programmes have become an effective mode of treatment delivery for teaching families effective behavioural strategies to manage challenging behaviours in young children with autism (G. Stahmer AM, 2001).

While the disorder is not rare, a majority of children with autism, even in urban India, have not been diagnosed and do not receive the services they need. This problem occurs in many countries, but is especially true in India, where there is a tremendous lack of awareness and misunderstanding is very common. In India low awareness levels and high levels of stigmatization, there is an increased need for public education programmes on the care of children with autism. Thus there is an urgent need to begin planning for the education of the caregivers in India. Not much work has been done in the Indian context focusing on parent's difficulties and struggles and how a parent can cope with them most effectively.

Even less is known about the levels of parental involvement in the whole process. Few studies have been conducted on the level of knowledge of caregivers on the care of children with autism. Also very limited studies were conducted on the effectiveness on parental educational interventions. Families of children with autism need adequate knowledge about care of children with autism. In a country like India, where the awareness about autism is still emerging, and the availability of services is in rather short supply, the role of the service provider would best be described as multifaceted—an information provider, a leader, a supporter, and a guide. There is a great need for the education of caregiver is high (Gupta, 2005).

Tonge B 2006 identified that the manual based parent education and behaviour management intervention was effective in alleviating a greater percentage of anxiety, insomnia, and somatic symptoms and family dysfunction than parent education and counselling at 6-month follow-up (Tonge B, Brereton A, Kiomall M, Mackinnon A, King N, 2006). So effective educational interventional programme need to be planned and implemented (Gupta, 2005).

When caring the child with autism the parents need to be confident and comfortable, so that they could support the child. The purpose of this research is to pro-

vide a teaching tool for the caregivers who involve in the training of young children with autism. It is intended that the book may be useful for the caregivers in handling the day today problems of children with autism at home. Research pertaining to educational intervention through information booklet for the caregivers of children with autism is minimal.

There is a significant need for educational intervention strategies with this population. Tertiary care setting like NIMHANS helps in diagnosis. But managing the children and assisting children to gain skills in different spheres of life lies in the hands of the caregivers. Therefore caregivers need information booklet as a source of knowledge about the care of children with autism.

In the view of the above the current study focuses on assessing the knowledge and opinion of the caregiver towards care of children with autism. Also the present study aims at developing and evaluating the effectiveness self instructional material in the form of information booklet for the care of children with autism on the level of knowledge and opinion, would help in finding out how instructional materials can be prepared and utilized effectively among the caregivers. Further more this study can have implications in finding out and modifying the problems children with autism.

Through research on children health is profoundly conducted in educational institutions and health centres it would reach the public only through social action programme aiming at comprehensive health education. Actually the relevance of such researcher is determined only when the propounded tenants are put into practice by the caregivers. In other words, the root of their happiness and unhappiness are inextricably intertwined with psycho social interiors of their family living. It is the caregivers in the family who need to help the children with the core deficits in autism, in this regard nurses who are in touch with both the children and caregivers can help through education.

The purpose of the study was to prepare the information booklet on care of children with autism for the caregivers and to evaluate the effectiveness of the information booklet on the level of knowledge of the caregivers in the care of child with autism.

Design:

A quasi experimental research design with

single group pre and post-test was adopted for the present study.

Setting and Population:

The study was conducted in the Child Psychiatry Centre, National Institute of mental health and Neurosciences (NIMHANS), Bangalore, Karnataka, India. Caregivers who attended the outpatient and inpatient Child psychiatric centre of NIMHANS, Bangalore were selected as the samples based on the inclusion and exclusion criteria. Inclusion criteria's were 1.Those care givers who are attending the outpatient and inpatient of child psychiatric centre of NIMHANS for the treatment of autism.2.Those caregivers whose children have been diagnosed as autism after the detailed workup is over.3.Those caregivers who understand, read and write English.4.Those caregivers of Children with autism between the ages of 4 – 14 yrs and 5.Those caregivers between the age group of 16 – 50 yrs. Exclusion criteria was the caregivers who had undergone any special course in the Care of children with autism.

Sample size and Method:

A purposive sampling technique was adopted for the present study to select subjects on the basis of inclusion and exclusion criteria. 30 caregivers of children with autism who were attending outpatient and inpatient Child psychiatric centre of NIMHANS, Bangalore selected as per the inclusion criteria.

Measures:

As there was no standard tool available to match the current study the tools were developed by the researcher. The relevant research and non-research literatures were reviewed for constructing the tools. Experts in the field of psychiatric nursing, psychiatry, and psychiatric social work were consulted for the opinion and suggestions in developing the tools. The following tools were used for the study.

Tool-1: Sociodemographic data schedule:

The Sociodemographic data schedule consisted of 14 items including various Sociodemographic details such as code of the caregiver, age of the caregiver ,gender of the caregiver, primary caregiver, caregiver

relationship the child ,marital status of the caregiver ,educational status of the caregiver ,occupational status of the caregiver ,income of the family ,residence,

state, mother tongue, any training in autism and willingness to know more about the condition

Tool -2 : Knowledge questionnaire on care of children with autism.

The knowledge questionnaire consisted of 30 multiple choice questions. The knowledge questionnaire was designed based on 5 dimensions such as Concept of autism, Signs and symptoms, causes and common problems of autism, assessment, Diagnosis & Interventions and Handling common behavioural problems at home.

Scoring:

Each correct answer was given a score of 1 and for wrong answer Zero. The maximum score was 30.Scoring interpretation is done based on the following <50% - inadequate knowledge, 50% - 75% moderate-ly adequate knowledge and >75% adequate knowledge.

Reliability:

Split half method was used to establish reliability of the knowledge questionnaire. For knowledge questionnaire the reliability was 0.9895 (Guttman split half method) which was highly statistically significant.

Information booklet:

An extensive literature review was done to find out the various dimensions of care of children with autism. Review of books on autism, child psychiatry, child psychology, parental manuals on autism, psychiatric nursing books were reviewed. Also extensive search was done in Medline, Psychinfo, EBSCO, Proquest, and Pubmedcentral to understand the content related to information booklet. Discussion with guides and specialists from department of Psychiatry, Psychiatric Nursing, Psychology and Psychiatric Social Work helped in identifying areas that should be covered in the booklet. With the information obtained from various sources, the content of information booklet was prepared. The content of the information booklet are Introduction to Autism, Facts and myths of autism, Signs and symptoms, Causes of Autism, Common problems that occur with autism, Assessment, Diagnosis and Interventions , Handling common behavioural problems at home, The National trust act , Websites for autism, Suggested readings for autism and Schools available for children with autism in Bangalore. 3 experts from Child Psychiatry, 3 from Psychiatric Nursing and 2 experts from Social Work vali-

dated the information booklet for applicability, feasibility, relevance, suitability and validity of its contents. Suggestions given by the experts with regard to the information booklet were duly incorporated and the information booklet was finalized. The information booklet was designed for learners to gain knowledge about the care of children with autism. The caregivers could study the information booklet whenever necessary. The subject matter was presented in simple language and it was organized in logical sequence.

Data collection procedure:

The researcher obtained permission from the department of Nursing, and Psychiatry for data collection at outpatient and inpatient of child psychiatric centre at NIMHANS. The participants were contacted for their willingness and consent to participate in the study. Socio-demographic details of the participants were obtained by administering the socio-demographic data sheet. The pre-test was administered by using the knowledge questionnaire. Soon after the data collection, the information booklet was given to the caregivers after a brief introduction to the topic. A period of 7 days was given to the caregivers for reading the information booklet. A post assessment was done by re-administering the same knowledge questionnaire. The caregivers in the outpatient settings were given a follow up date after one week whereas the caregivers in the inpatient were met after one week by the researcher. Knowledge scores were measured before the administration of information booklet. The information booklet was then introduced and their level of knowledge was reassessed. The effectiveness of the information booklet was then determined by comparing the pre-test and post test scores on the level of knowledge of the caregivers.

Results and Discussion

Sociodemographic data:

Approximately half of the caregivers (43.3%) participated in the study were between the age group of (35 – 40 yrs). A higher percentage (36.7%) of the caregivers were in the age group of 29-34yrs. A less percentage (3.3%) of the caregivers were in the age group of 23 – 28 years. These study findings were similar to the study conducted by Tonge B, Brereton A, Kiomall M, Mackinnon A, King N and Rinehart N. (2006) where the majority of the caregivers age were between 28-43 years (Tonge B, Brereton A, Kiomall M, Mackinnon A, King N, 2006).

Majority of the caregivers participated in the study were females (86.7%) where as a less percentage of the caregivers were males (13.3%). This implies that the majority of the females were the primary caregivers. This study finding was similar to the study finding conducted by Mercer.L, Creighton.S, Holden J JA. and Lewis MES. (2006) in which majority 90% of the parents participated in study were females (Mercer L, Creighton S, Holden J J A, 2006).

All the caregivers (100%) participated in the study were primary caregivers. This showed that both males and females were taking the role of primary caregivers in caring the children with autism. This study finding was similar to a study conducted by Frazee .L.B. (2004) in which all the participants in the study were primary caregivers (Frazee, 2004).

A high percentage of the caregivers participated in the study were mothers (86.7%). and a least percentage (13.3%) of the caregivers were fathers. This showed that all the caregivers are primarily the parents not any other relatives. This study finding was similar to the study finding conducted by Mercer L, Creighton S, and Holden JJA. and Lewis MES (2006) in which majority (90%) of the parents participated in study were mothers (G. K. Stahmer AM, 2001).

All the caregivers participated in the study were married (100%). This study finding was similar to the findings of the study conducted by Stahmer.A.C and Gist.K (2001) where majority (98%) of the caregivers were married (Kasari C, Freeman FN, Bauminger N, 1999).

Half of the caregivers were post graduates (50%), approximately half of the caregivers were graduates (46.7%) and a least percentage of 3.3% were educated upto PUC. These results showed that the caregivers who were highly educated were coming forward for the treatment of children with autism. These findings were similar to a study conducted by Kasari.C, Freeman.F.N, Bauminger.N, and Alkin.N.C. (1999) in which majority of the caregivers (38%) were studied beyond Bachelor's degree and only 6 % of them studied up to high school (Perry A, Prichard E.A, 2006).

Regarding the occupational status about half of the caregivers were employed in private (43.3%), one fourth of the caregivers were working in government (30%) and the others caregivers were house wives/home maker (26.7%). This showed that majority of the care-

givers were working. Both the parents were going for work had become the essential need of the life to meet the increased cost of living. Higher percentage of the caregivers family income was between 5,000-30,000 (73.3%), and a very least percentage of the caregivers family income was about 55,001- 85,000 (6.7%). 20% of the caregivers family income was between 30,001 – 55,000 .

About two third of the caregivers were from urban area (76.6%) and one third of the caregivers were from rural area (23.3%). This showed that the caregivers from urban area were aware of the condition of the child and there were accessing the facilities available in NIMHANS. Majority of caregivers were from Karnataka (36.7%), others were from Tamilnadu (10%), Kerala (16.7%), West Bengal (23.3%), Orissa (3.3%), Maharashtra (3.3), Assam (3.3%), Jhagarkand (3.3).

This would be because the hospital had been catering to the mental health needs of population of all age groups even prior to independence to India and had established popularity for its service. Also it indicates that caregivers from Karnataka as well as from other states of India were utilizing the services available in NIMHANS.

Majority of the caregiver's mother tongue was Bengali (26.7%) and minority had their mother tongue as Hindi (3.3%) and Marvadi (3.3%). This would be because that many of the caregivers were from West Bengal and also caregivers speaking different languages got settled in Karnataka.

Majority of the caregivers were from nuclear family (56.7%) and a moderate percentage of the caregivers were from joint family (33%) and others (10%) were from extended family. It indicates that majority of the children with autism were from the nuclear families. Technological advances made the job available for the rural population to get migrated to cities and to form a nuclear family.

Almost two third of the caregivers were having 3 -4 members (66.7%) in the family and least percentage of the caregivers had 7-8 members (6.7%) in the family. 26.7% of the caregivers had 5 -6 members in their family. This indicated that majority of the children with autism were from the family consisting of less family members.

This could be because that India's one of the health policies was to reduce the finding size to control population explosion. All the caregivers (100%) did not had any training in autism in the present study. This suggested that the caregivers were not undergoing any training in autism. This would be because they were unaware about the training programme or less availability of the training facilities.

These study findings were contrary to a study conducted by Perry A, Prichard EA. and Penn H E. (2006), where 85% of the parents had attended professional workshops on Intensive behavioural intervention for children with autism spectrum disorder (Perry A, Prichard E.A, 2006). When the caregivers were asked whether they wanted to know more about autism, all thirty caregivers (100%) reported yes. This showed that all the caregivers had the learning needs to know more about the children's condition. All the caregivers (100%) were aware of their child's diagnosis of Autism. This indicated that the caregivers been told about the child's problem when they come to NIMHANS.

Effectiveness of the information booklet on the care of children with autism:

As the table 1 shows, in the concept of autism dimension (dimension one) the pre-test mean score was 1.93, mean percentage was 48.32% and post-test mean score was 3.33 ,mean percentage was 83.32% ,knowledge gain was 1.4 , paired t value was 6.96 and p value was 0.000 which was highly significant.

In the signs and symptoms of autism dimension (dimension two) the pre-test mean score was 3.9, mean percentage was 65% and post-test mean score was 5.46, mean percentage was 91.1%, knowledge gain was 1.56, paired t value was 04.41 and p value was 0.000 which was highly significant.

In the causes and common problems of autism (dimension three) the pre-test mean score was 2.86, mean percentage was 71.65 % and post test mean score was 3.8 ,mean percentage was 95% ,knowledge gain was 0.94 ,paired t value was 4.59 and p value was 0.000 which was highly significant.

In the assessment, diagnosis and intervention for autism (dimension four) the pre-test mean score was 3.1, mean percentage was 38.75 % and post test mean score was 5.66 ,mean percentage was 70.82% ,knowledge gain was 2.56 ,paired t value was

Table I. Dimension wise comparison of pre and post test scores on knowledge (n=30)

Knowledge dimension	Pre test/	Mean pretest scores	% of mean pre-test	Knowledge gain	Standard deviation	t- value	p value
Concept of autism	Pre test	01.93	48.32	1.4	01.20	6.96	< 0.001
	Post test	03.33	83.32				
Signs and symptoms of autism	Pre test	03.90	65.00	1.56	02.20	04.41	< 0.001
	Post test	05.46	91.10				
Causes and common problems of autism	Pre test	02.86	71.65	0.94	01.16	04.59	< 0.001
	Post test	03.80	95.00				
Assessment ,diagnosis and intervention for autism	Pre test	03.10	38.75	2.56	01.74	08.60	< 0.001
	Post test	05.66	70.82				
Handling common behaviour problems of children with autism at home. (KD5)	Pre test	03.10	38.75	2.60	01.47	11.40	< 0.001
	Post test	05.70	71.25				
Overall	Pre test	14.899	49.66	9.07	07.78	35.99	< 0.001
	Post test	23.965	79.88				

8.60 and p value was 0.000 which was highly significant.

In the handling common behaviour problems of children with autism at home (dimension five) the pre-test mean score was 3.1,mean percentage was 38.75 % and post test mean score was 5.7 ,mean percentage was 71.25% ,knowledge gain was 2.6 ,paired t value was 11.4 and p value was 0.000 which was highly significant.It was inferred that in all the five dimensions the subjects gained knowledge at significant level by the effect of the information booklet, which was given to the caregivers of children with autism.

As the caregivers were living with the problems of their children their knowledge score in the dimension of causes and common problems (third dimension) was high in the post test. Also in the dimension of concept of autism (first dimension) and signs and symptoms (second dimension) the caregivers were aware of it they were able easily understand it, so their score on these dimensions were also adequate.

As the caregivers were not having the background for the understanding of the medical procedures they scored only moderately adequate knowledge in the dimension of assessment, diagnosis and intervention (fourth dimension) and handling the common behaviour problems at home (fifth dimension).

Tonge B, Brereton A, Kiomall M, Mackinnon A, King N and Rinehart N (2006) conducted a randomized control trial on education and skills training program for parents of young children with autism in the hospital setting. The study aims to determine the impact of a parent education and behaviour management intervention (PEBM) on the mental health and adjustment of parents with preschool children with autism.

The parent education and behaviour management intervention was effective in alleviating a greater percentage of anxiety, insomnia, and somatic symptoms and family(Tonge B, Brereton A, Kiomall M, Mackinnon A, King N, 2006). Yet another study finding was similar to that of present study wherein Probst_P. (2003)

evaluated the effectiveness of psycho educational programmes conducted for the parents of children with autism and found knowledge score improvement in the post test(Probst, 2003).

This findings were similar to that of study findings of Leslie J J, Oscar G, Della B, Jane B and Joseph R K(1998) where in it revealed that there were greater gains in language abilities, significant increase in caregivers' knowledge about autism, greater perception of control on the part of mothers, and greater parent satisfaction after the intervention (Leslie JJ, Oscar G, Della B, Jane B, 1998)

Association between selected socio demographic variables and post knowledge scores.

The selected socio demographic variables and the post-test knowledge scores were statistically analyzed for their association. It was found that only three variables were having association with the post-test knowledge scores namely type of schooling of the children, gender of the caregiver and the relationship of the caregiver to the child. The remaining variables such as currently in therapy, past therapy, age of the caregiver, education level of the caregiver, occupational status of the caregiver, monthly family income, residence, state, mother tongue and family history of speech delay and MR had not shown statistically significant association with the post-test knowledge scores.

Limitations:

Due to the lack of availability of enough samples the study was conducted in two different settings such as outpatient and inpatient settings. Also the study subjects were limited to only 30 subjects. Smaller sample size made it difficult to generalize the findings. Long term follow up evaluation was not done due to time constraint.

Suggestions for future research

- The study can be replicated with larger sample to generalize the findings.
- Using true experimental design, independent effects of the information booklet can be assessed.
- A follow up programme can be done to determine the long term effect of the information booklet.
- A study may be conducted to compare the effect of the information booklet on the caregivers in the inpatient and outpatient department.
- A study can be done to compare efficacy of information booklet with other education teaching strategies.

information booklet with other education teaching strategies.

- It was also recommended that the study could be replicated using a randomization and a larger sample having control group to improve the external validity of the research design.
- Application of the knowledge of caregivers in the home care setting can be studied.
- Using a qualitative research approach is an appropriate method to the study the opinion may be undertaken. Thus a qualitative study can be implied to investigate the essence of opinion among caregivers about the care of children with autism.

Conclusion:

This study had shown that the information booklet can increase the level of knowledge of caregivers regarding the care of children with autism. There fore it is concluded that the information booklet was effective in improving the knowledge of the caregivers towards the care of children with autism and helped in strengthening the positive. It also helped in creating a positive opinion among the caregivers towards the care of children with autism. Caregivers who read the information booklet can bring out long-term change in the children's behaviour there by improving their quality of life.

Reference:

- Frazee, B. (2004). Using parent/clinician partnerships in parent education programs for children with autism. *Journal of Positive Behaviour Interventions*, 6(4), 195–213.
- Gray DE. (1992). . Psychosocial Well-Being among the Caregivers of Children with Autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18, 83–93.
- Gupta, A. (2005). Psychosocial support for families of children with autism. *Asia Pacific Disability Rehabilitation Journal*, 16 (2), 62–83.
- Jones, G. (1997). Disabling Children: Autism, the Effect on Families and Professionals. *Educational and Child Psychology*, 14(3), 71–76.
- Kasari C, Freeman FN, Bauminger N, A. M. (1999). Parental Perspectives on Inclusion: Effects of Autism and Down Syndrome. *Journal of Autism and Developmental Disorders*, 29(4), 297–305.
- Koegel LK, Koegel RL, Kellegrew D, M. K. (1996). Parent education for prevention and reduction of severe problem behaviours. *Positive Behavioural Support*, 81–98.
- Leslie JJ, Oscar G, Della B, Jane B, J. R. (1998). Treatment of Children with Autism: A Randomized Controlled Trial to Evaluate a Caregiver-Based Intervention Program in Community Day-Care Centers. *Journal of Developmental & Behavioural Pediatrics*, 19(5), 326–334.

- McConachie H, D. T. (2007). . Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of Evaluation of Clinical Practice*, 13(1), 120–129.
- Mercer L, Creighton S, Holden J J A, L. M. E. (2006). Parental Perspectives on the causes of an autism spectrum disorder in their children. *Journal of Genetic Counseling*, 15(1), 41–50.
- Perry A, Prichard E.A, P. H. . (2006). Indicators of quality teaching in intensive behavioural intervention: a survey of parents and professionals. *Behavioural Interventions*, 85–96.
- Probst, P. (2003). Development and evaluation of a psycho educational parent group training program for families with autistic children. *Prax Kinder Psychologie and Kinder Psychiatrie*, 52(7), 473–490.
- Sanders JL, M. S. B. (1997). Family Stress and Adjustment as Perceived by Caregivers of Children with Autism or Down syndrome: Implications for Intervention. *Child and Family Behaviour Therapy*, 19(4), 15–32.
- Schieve LA, Blumberg SJ, Rice C, Visser SN, B. C. (2009). Autism and Parenting Stress: The relationship between autism and parenting stress. *American Academy of Pediatrics*, 114–121.
- Stahmer AM, G. (2001). The effects of an accelerated parent education program on technique mastery and child outcome. *Journal of Positive Behaviour Interventions*, 3(2), 75–82.
- Stahmer AM, G. K. (2001). The effects of an accelerated parent education program on technique mastery and child outcome. *Journal of Positive Behaviour Interventions*, 3(2), 75–82.
- Tonge B, Brereton A, Kiomall M, Mackinnon A, King N, R. N. (2006). Effects on parental mental health of an education and skills training program for parents of young children with autism: a randomized controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45(5), 561–569.
- University Centre for Excellence in Developmental Disabilities Education, Research, and S. (2007). *Enhancing Early Intervention for Parents of Young Children with Autism Spectrum Disorders: Information, Strategies, and Resources* (pp. 1–27).
- Whitelaw C, Flett P, A. D. . (2007). Recurrence risk in Autism Spectrum Disorder: a study of parental knowledge. *Journal of Pediatric Child Health*, 43(11), 752–754.
- WHO. (2003). *Caring for children and adolescents with mental disorders - Setting WHO directions* (pp. 2–9).
- Wolff, S. (2004). The history of autism. *European Child and Adolescent Psychiatry*, 13, 201–208.