## LIFE SPAN AND DISABILITY

Vol. XIII / n. 2 / July - December 2010

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Journal promoted by the Department of Psychology
Institute for Research on Mental Retardation and Brain Ageing “Oasi Maria SS.” - Troina
LIFE SPAN AND DISABILITY
Psychology, Social issues, Education, Rehabilitation, Habilitation

Promotes interdisciplinary research about psychological, social, educational, rehabilitative and neuro psychological aspects of the human life span. The aim is to give diffusion to the scientific studies of persons who have to cope with cognitive and emotional and interpersonal problems – for transient or persistent reasons – in the different periods of life, when specific existential events (e.g., adolescence, loss of work, retirement, end of fertility, normal and pathological aging) could cause disease or actual disability. The neuropsychological and social aspects of Intellectual Disability, and the strategies to enhance the cognitive rehabilitation and the quality of life of these persons, were a main target in the published studies. The attention is focused, for the different phases of life and for the specific conditions of disease, on the skills suitable to promote the person’s development, fully using all the existing or residual potentialities. The view to consider these aspects may be in turn educational, social, environmental, but taking into account the connections with the bio-psychological bases and/or with the data derived from empirical research. Both quantitative and qualitative methodological approaches are welcomed.

The contributions received are submitted to two members of the scientific committee, for a blind peer-review process.

Two issues per year will be edited, in English language, and published online on the website www.lifespan.it. Each issues will include research contributes, reporting original theoretical, methodological or empirical studies; diagnostic or intervention instruments (validation of techniques as tests or grids in the field of interest of the Journal); case-reports of clinical or rehabilitative relevance; reviews on specific themes.

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LIFE SPAN AND DISABILITY

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Comments on a study of the social validity of the developmental disability parent training program Stepping Stones Triple P

Trevor G. Mazzucchelli, Lisa J. Studman, Koa Whittingham & Kate Sofronoff

Abstract

Probst, Glen, Spreitz, and Jung (2010) described an evaluation of the social validity of the parenting intervention Stepping Stones Triple P (SSTP). In this evaluation, 33 masters-level psychology students viewed one of the program resources and rated the strategies of quiet time and time out as lacking in both ethical acceptability and practical applicability. On the basis of this, the authors recommended revisions to the content of SSTP. The present paper provides additional information about SSTP to correct possible misconceptions, and provide further comments on Probst and colleagues’ (2010) findings. SSTP has been demonstrated to be effective with a range of parents of children with diverse developmental disabilities and there is considerable support for the validity and effectiveness of the specific elements in question. Given this, it is argued that while there will inevitably be variations in how individuals accept program content, rather than altering program, it may be more appropriate to address those variables related to the acceptability of content. To this end, it is suggested that future research could usefully investigate

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The authors thank Alan Ralph for his useful comments on a draft of this manuscript. ThomasDirscherl and Barbara Hirche for their assistance in accessing practitioner data and Grace Sweeney for her assistance with analysing these data.
influences on perceptions of content and, in particular, practical strategies to overcome barriers to the acceptance of socially valid and empirically supported methods.

Keywords: Parent training, Developmental disability, Stepping Stones Triple P, Social validity, Time out
Study of the social validity of the developmental disability parent training program Stepping Stones Triple P

In a recent paper that appeared in this Journal, Probst, Glen, Spreitz, and Jung (2010) described an evaluation of the social validity, in a German context, of some of the content of the parenting intervention Stepping Stones Triple P (SSTP; Sanders, Mazzucchelli, & Studman, 2004, 2010). In this evaluation, 33 masters-level psychology students viewed one of the program resources (Stepping Stones Triple P: A survival guide video; Sanders, Mazzucchelli, & Studman, 2005) and rated the content in terms of its ethical acceptability and practical applicability. A total of 24 of these students provided further qualitative comments on the video. The authors reported that 21 of the 25 strategies depicted on the video were evaluated positively both in terms of ethical acceptability and practical applicability. However one strategy, “planned ignoring”, was evaluated neither positively nor negatively in terms of its ethical acceptability, the strategy “diversion to another activity” was evaluated negatively on practical applicability, and the strategies of “quiet time” and “time out” were evaluated negatively both in terms of ethical acceptability and practical applicability. On the basis of this subjective evaluation and the qualitative feedback from masters-level psychology students the authors made suggestions regarding the partial revision of program materials. The present paper provides additional information about SSTP to correct some possible misconceptions regarding the program, and provides further comments on the interpretation and implications of Probst et al.’s (2010) findings. It also presents evaluation data from an international sample of professionals and paraprofessionals who have undergone training in the use of SSTP. This data reflects practitioners’ satisfaction with training, program content and self-reported confidence in conducting parent consultations pre-and post-training.

What is the Stepping Stones Triple P-positive parenting program?

SSTP is a multilevel system of parenting intervention designed to improve the quality of parenting advice available to parents of children who have a developmental disability (Sanders et al., 2004, 2010). SSTP represents a parallel version of the core Triple P-Positive Parenting Program, which was developed for children who are developing typically (Sanders, 1999). The Triple P system aims to foster positive, caring relationships between parents and their children, promote children’s development, and prevent behavioural and emotional problems in children by enhancing the knowledge, skills, and confidence of parents.
The suite of multilevel programs includes intensive individually delivered face-to-face interventions, group interventions, more cost- and time-effective brief interventions, large group seminars and media based interventions (see Sanders, 1999, for an overview of Triple P). The rationale for this tiered multilevel system is that there are different levels of difficulty in the behaviour problems of children, and parents have differing needs and desires regarding the type, intensity and mode of assistance they may require. This flexibility enables parents to participate in parent education in ways that suit their individual circumstances, and the level of support provided to parents can be increased or decreased as indicated. This multilevel strategy is designed to maximize efficiency, contain costs, avoid waste and over servicing, and ensure the program has a wide reach in the community.

Positive parenting with children with a developmental disability

SSTP is based on a number of contemporary theoretical perspectives in psychology including learning theory and applied behaviour analysis (Baer, Wolf & Risley, 1968), developmental research on social competence (Hart & Risley, 1974, 1995), research on risk and protective factors (Patterson, 1982; Rutter, 1990), cognitive social learning theory (Karoly, 1993; Bandura, 2000), and normalisation and social role valorisation (Wolfesnberger, 1983; Nirje, 1985). Seven core positive parenting principles form the basis of the program: (a) safe and engaging environment, (b) positive learning environment, (c) assertive discipline, (d) adaptation to a child with a disability (e) realistic expectations, (f) community participation, and (e) parental self-care. These principles were selected to address specific risk and protective factors known to predict developmental and mental health outcomes in children with developmental disabilities. They are operationalised into a range of specific parenting strategies (Sanders et al., 2004, 2010). The 25 strategies within SSTP are drawn from the disabilities research literature. Only strategies that have been empirically demonstrated to be reliably effective for children with developmental disabilities are included (e.g., incidental teaching, McGee, Krantz, & McClannahan, 1985; teaching backwards, Hagopian, Farrell, & Amari, 1996; teaching your child to communicate what they want, Tait, Sigafoos, Woodyatt, O’Reilly, & Lancioni, 2004; brief interruption, Azrin, Besalel, Jamner, & Caputo, 1988).

Process: Self-regulation of parenting skills

A central goal of Triple P is the development of an individual’s capacity for self-regulation. Self-regulation is a process whereby individuals change their own behaviour and become independent problem solvers
Consultation processes are employed in SSTP such that parenting competence is enhanced while simultaneously building parents’ capacity for self-regulation (e.g., Sanders & Lawton, 1993; Sanders, Mazzucchelli, & Ralph, in press). These consultation processes result in SSTP being “family-centred” in that parents set their own goals and play an active role in the assessment and intervention process. Parents choose the child behaviours they wish to target and monitor, develop hypotheses as to why the behaviour is (or is not) occurring, and select the specific parenting strategies they wish to use. SSTP emphasises the teaching of functional skills for children, rather than suppressing unwanted behaviour. Parents are taught a range of prevention and planning skills to facilitate the development of multifaceted parenting plans which incorporate changes to the environment as well as changes to the antecedents and the consequences of behaviour. The implementation of a plan is monitored and parents are encouraged to review progress with their practitioner within one to two weeks.

Practitioner training

Practitioner training is a requirement for use of SSTP materials. SSTP practitioner training has two attendance components. The initial component provides instruction in both the theory and practice of providing parenting and behaviour management advice to parents who have a child with a disability. The second attendance component is a competency-based accreditation workshop in which practitioners demonstrate their knowledge of and skill in delivering SSTP. Practitioner training provides opportunities for practitioners to develop a thorough understanding of the rationale and principles of SSTP content, and competence in the effective and appropriate delivery of the program (Mazzucchelli & Sanders, 2010). Almost 1,800 practitioners from ten countries have been trained to provide SSTP interventions since 2006, with Australia (705), Canada (439) and England (375) having had the most practitioners trained. Practitioners from other countries who have been trained include those from Belgium (16), Germany (99), Hong Kong (32), Ireland (19), Netherlands (49), Scotland (19) and Singapore (40). Regardless of their nationality, practitioners consistently rate the content of SSTP practitioner training between good (5) and excellent (7) and their overall satisfaction with SSTP training between satisfied (5) and very satisfied (7) on seven-point Likert-type scales (mean ratings of 6.17 and 6.19 respectively, see Table 1). Practitioners also report an increase in self-efficacy in a range of parent consultation tasks, such as conducting effective behavioural rehearsal with parents. Table 2 presents participant responses to a 20-item questionnaire on proficiency in parent consultation skills for samples of practitioners from various countries trained since 2006. Responses range from 1 (not at all proficient and would like assistance) to 7 (extremely profi-
Table 1 - Mean ratings for satisfaction with workshop content and overall satisfaction of practitioner training

<table>
<thead>
<tr>
<th>Level of Triple P</th>
<th>Content</th>
<th>Overall</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
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<td>5.86</td>
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<tr>
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<td>78</td>
<td>6.22</td>
<td>.83</td>
<td>6.22</td>
</tr>
<tr>
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<td>6.36</td>
<td>.73</td>
<td>6.20</td>
</tr>
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<td>6.07</td>
<td>.59</td>
<td>6.13</td>
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<td>6.10</td>
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<td>39</td>
<td>6.28</td>
<td>.67</td>
<td>6.15</td>
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</tbody>
</table>

Note: Ratings for content were based on a seven-point Likert-type scale where 7 = excellent, 5 = good, 3 = fair, and 1 = poor. Ratings for overall satisfaction were based on a seven-point Likert-type scale where 7 = very satisfied, 5 = satisfied, 3 = dissatisfied, and 1 = very dissatisfied.
Table 2 - Mean ratings for overall proficiency in parent consultation skills before and after practitioner training

<table>
<thead>
<tr>
<th>Level of Triple P</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>F</th>
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<tr>
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<td>0.73</td>
<td>5.71</td>
<td>0.46</td>
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<td>5.86</td>
<td>0.62</td>
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<td>5.56</td>
<td>0.38</td>
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<td>1.01</td>
<td>5.40</td>
<td>1.00</td>
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</table>
cient, no assistance required). Measures were taken pre-, post- and at a follow-up to training. Significant improvements over time for all levels of training are indicated. Corresponding to improvements in self-reported proficiency, Triple P training has been demonstrated to result in improved parent consultation skills as assessed by independent behavioural observation (Sanders, Tully, Turner, Maher, & McAuliffe, 2003).

### Life Span and Disability

### Mazzucchelli T.G. et al.

<table>
<thead>
<tr>
<th>Level of Triple P</th>
<th>Pre-training</th>
<th>Post-training</th>
<th>Follow-up</th>
<th>F ratio for Time Effect</th>
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<td>39</td>
<td>3.97</td>
<td>0.83</td>
<td>5.26</td>
</tr>
</tbody>
</table>

Note:
Ratings for overall proficiency in parent consultation skills were based on a seven-point Likert-type scale where 7 = extremely proficient, no assistance required, and 1 = not at all proficient and would like assistance.
Program materials

A range of program materials exists to support the delivery of SSTP. These include practitioner manuals, training manuals, parent workbooks, a DVD, and topic specific booklets that include comprehensive behaviour support plans. Practitioner manuals include detailed descriptions of how to undertake various intervention tasks including assessment, delivery of SSTP content, and the management of process issues. Training manuals include information beyond what is included in practitioner manuals about how to prepare for and implement the intervention. Parent materials provide enough detail so that the parent can decide whether each individual strategy is acceptable to them, can follow suggested parenting plans, and can generalise the strategies to other situations. Relevant to this commentary, the SSTP Survival Guide video that was used in Probst et al.’s (2010) evaluation presents a subset of the parenting skills included in SSTP and is typically used to complement consultations with a trained SSTP provider, and in conjunction with other SSTP parent materials. The SSTP Survival Guide DVD is not intended to be delivered as a stand-alone intervention; rather, it is supplementary material to a complete intervention, which incorporates functional assessment assisted by an accredited practitioner. Some of the qualitative feedback given by participants in Probst et al.’s (2010) evaluation indicates that they may have misunderstood this and instead judged the DVD as a stand-alone intervention. For example, it was stated that concepts such as “realistic expectations” are not adequately defined in the video. This concept is introduced in the DVD and then practitioners discuss it in a manner relevant to each family’s context. This misunderstanding may have affected the participants’ qualitative feedback on SSTP broadly.

Effectiveness of SSTP

SSTP has been subjected to a series of randomised controlled trials and has been demonstrated to be acceptable to parents and effective in changing risk and protective factors and producing better mental health and developmental outcomes in children than comparison conditions. Participants in existing research have included parents of children with intellectual, physical, and sensory disabilities and pervasive developmental disorders including autistic disorder and Asperger’s syndrome (Harrison, 2006; Roberts, Mazzucchelli, Studman, & Sanders, 2006; Whittingham, Sofronoff & Sheffield, 2006; Plant & Sanders, 2007; Whittingham, Sofronoff, Sheffield, & Sanders, 2009b; Hampel, Hasmann, Schaadt, Holl, Petermann, & Hasmann, 2010; Hampel, Schaadt, Hasmann, Petermann, Holl, & Hasmann, 2010). Although most of these studies have been conducted in Australia, one has been conducted in Germany to good effect.
Acceptability of SSTP

The acceptability of parenting strategies is an important issue since the perceived lack of acceptability or practical applicability of an intervention could act as a barrier to the uptake of empirically supported interventions. Parents who view strategies as unacceptable or impractical may not attempt potentially useful and effective strategies. Similarly, practitioners who view strategies as unacceptable or impractical may not be convincing advocates for a potentially effective program, withhold program content from parents, or actively discourage parents from using strategies. It is worth noting, however, that low acceptability of a specific intervention on the part of parents and professionals does not necessarily mean that this intervention should be changed. If an intervention has been shown to be effective it may be more appropriate to educate parents and professionals to correct misunderstandings and reduce barriers to program implementation.

Previous research investigating the acceptability of SSTP with parents of children who have a developmental disability have reported high ratings for SSTP’s acceptability (Roberts et al., 2006; Whittingham et al., 2006; Plant & Sanders, 2007; Whittingham, Sofronoff, Sheffield, & Sanders, 2009a; Whittingham, Wee, Sanders, & Boyd, in press). However, these data seem at odds with those of Probst et al.’s (2010) study where acceptability and usability ratings by masters level psychology students with little experience consulting parents of children with developmental disabilities appeared to be lower generally. It should be noted that it is not without precedent that a lack of correspondence has been found between the ratings of strategies by practitioners and parents. For instance, Morawska (2010) reported that practitioners rated Triple P strategies as substantially less acceptable and useful for culturally and linguistically di-
verse parents than those parents rated the same strategies for themselves. Whittingham *et al.* (in press) recently reported a similar discrepancy specifically in relation to time out between practitioners and parents of children with cerebral palsy.

It should also be noted that the evaluations of the masters level psychology students may change as they acquire clinical experience using strategies with families. This also is not without precedent. Parents of children with ASD who viewed the SSTP Survival Guide video expressed concerns about using the strategy time out as well as strategies that use physical touch such as physical guidance (Whittingham *et al.*, 2006). However, the majority of parents of children with an autism spectrum disorder who received SSTP in a randomised controlled trial chose to use the strategies of time out (75%) and physical guidance (81.8%) and reported them to be effective (Whittingham *et al.*, 2009a). Thus, the opinions of parents and professionals on the acceptability and usability of parenting strategies following a brief viewing of program materials cannot be relied upon to indicate how acceptable and usable they will find the strategies once they have been adequately trained in their implementation in the context of a complete parenting intervention.

### Inclusion of time out

Probst *et al.* (2010) reported that the non-exclusionary quiet time, and exclusionary time out procedures were the only strategies to be evaluated negatively by the students with regard to their ethical acceptability. In the light of these ratings, qualitative reports from students, and the opinions of some who have previously commented on time out (e.g., Harris, 1998; Bregman, Zager, & Gerdtz, 2005), Probst *et al.* (2010) recommended that these procedures should be marked as a unique and last-resort intervention to be used only if all less restrictive methods have failed. However, research evidence does not support the notion that time out should be a restricted procedure or presented in this way.

Although most of the existing research has been done with samples of children who are developing typically, there is considerable evidence that time out, when used in combination with other positive parenting methods, can be an effective strategy for reducing child noncompliance and aggressive behaviour over and above the effects of praise, rewards, use of effective instructions and other behaviour management strategies (Roberts, Hatzenbuehler, & Bean, 1981; Hobbs, Walle, & Caldwell, 1984; Ford Olmi, Edwards, & Tingstrom, 2001; Fabiano, Pelham, Manos, Gnagy, Chronis, Onyango *et al.*, 2004; Kaminski, Valle, Filene, & Boyle, 2008). Furthermore, time out has the additional benefit of assisting children to regulate their emotions, by providing an opportunity for the child to calm down,
and to learn to manage difficult and frustrating situations (Morawska & Sanders, in press).

It should also be noted that time out is used as one of a number of strategies in most evidence-based parenting programs for parents of young children including Parent-Child Interaction Therapy (Eyberg, 1988), Parent-Management Training Oregon model (Patterson, 2005), and The Incredible Years Program (Webster-Stratton, 1998). Over the three decades in which time out has been used as part of these programs, no evidence has emerged that these programs are damaging or create subsequent childhood behaviour problems. On the contrary, there is good evidence that such programs prevent the development of more severe problems (Cunningham, Bremner, & Boyle, 1995; Webster-Stratton, 1998; Zubrick, Ward, Silburn, Lawrence, Williams, Blair et al., 2005).

Time out has the support of many professional societies such as the American Academy of Pediatrics (1998). It is widely used by parents (Sanders, Tully, Baade, Lynch, Heywood, Pollard et al., 1999), and parents who have been trained in the use of time out rate it as an acceptable and effective strategy including parents of children with autism spectrum disorders (Hobbs et al., 1984; Roberts et al., 2006; Whittingham et al., 2009a). Children also rate time out as an appropriate strategy for parents to use (Dadds, Adlington, & Christensen, 1987).

Concerns about time out are often based on the assumption that the strategy is used in isolation (Morawska & Sanders, 2010). However, SSTP, along with other evidence-based parenting programs, only use time out in combination with other strategies and in the context of a positive parent-child relationship. SSTP provides parents with a framework to understand why behaviour occurs, the principles by which time out and other strategies are effective, and the contexts in which time out might be useful. Parents are provided with information on how to use time out appropriately, what they might expect if they use time out, and how to minimise pitfalls. If parents decide to use time out, they are encouraged to monitor their use of the procedure and the behaviour they are seeking to modify. They are also provided with instructions on what to do should their parenting plan (whether it includes time out or not) not be effective.

Probst et al. (2010) quote from an Australian review of positive behaviour support programs by Weise, Stancliffe and Hemsley (2005) that suggested that the use of time out might be of concern to the Department of Ageing, Disability and Home Care (DADHC) in New South Wales, Australia. DADHC commissioned this review in order to identify a preferred approach to be adopted within the agency. The reviewers set evaluation benchmarks based on national and international literature to compare programs based on best practice in designing positive behaviour support programs for families, implementation processes, and outcomes for child and family. They concluded that SSTP was the preferred program with
many merits over other programs. However, it was noted that the use of
time out might have implications for DADHC given its (2003) policy on
restrictive practices. The 2009 Behaviour Support Policy (Office of the Se-
nior Practitioner, NSW DADHC, 2009) supersedes the 2003 policy
(DADHC, 2003) and outlines minimum requirements for DADHC ser-
vice providers with respect to behaviour support. Within the current poli-
cy a number of practices including exclusionary time out and response
cost are recognised as strategies that require additional safeguards when
service providers incorporate them into documented behaviour support
plans; namely, conditions that must be met for each of these strategies to
be recommended. These conditions are consistent with the way that the
strategies are taught and supported during SSTP interventions. Over 115
practitioners have been trained and accredited in SSTP in NSW, Aus-
tralia, since 2006 (McWilliam, 2010).

It is important that misinformation about time out and its adverse ef-
fects on children does not lead to parents being denied access to poten-
tially effective interventions, especially for a population at substantially
greater risk of developing emotional and behavioural problems (Tonge &
Einfeld, 2000; Dekker, Koot, van der Ende, & Verhulst, 2002; Emerson,

Depiction of strategies in the DVD

Probst et al. (2010) criticises five scenes in the SSTP Survival Guide
DVD, which depict the use of discipline strategies. Criticisms included
that the problem behaviour did not justify the strategy (quiet time used to
back up an instruction after a child continues to throw toys), it was not
clear why the discipline strategy was being used (depiction of a child be-
ing taken to and later brought out from time out, child placed in time out
after pinching mother), that the depiction looked staged and that a less
restrictive strategy could have been used (time out used after a child re-
fuses to put on shoes and then does not remain seated in quiet time), and
that the use of directed discussion was over-directive and stifled appro-
priate play (boy hitting a toy boat with a hammer instead of the toy ham-
mering pegs).

In responding to these criticisms it is important to recognise that the
primary purpose of the DVD is to illustrate key aspects in the implemen-
tation of SSTP strategies; that is, how strategies are implemented, but not
necessarily when. Hence it is the implementation of strategies that is pre-
sented without a larger functional context that may have caused the con-
cerns of Probst et al. (2010). While it is our contention that all the exam-
pies depict acceptable implementation of the strategies, this is not to say
that the examples illustrate the only way a parent could have responded
in the scenarios depicted. As stated earlier in this paper, a guiding principle underpinning SSTP is that parents learn to direct their own behaviour, selecting personal goals for their own and their child’s behaviour, and choosing which of the SSTP strategies presented are acceptable and appropriate in their personal circumstances. When necessary, it is the practitioner’s role to help parents recognise the principles underpinning the strategies and discuss where and how they might be usefully employed; however, ultimately it is the parents who choose which strategies they wish to use and in which circumstances. To the extent that the depiction of these strategies adversely influences perceptions of their acceptability (e.g., because of the staged nature of the depiction), the authors will attempt to address these issues in future iterations of the DVD.

Conclusion and future directions

Probst et al.’s (2010) paper reported that a sample of 33 inexperienced German masters level students of psychology who viewed the SSTP survival guide parent video rated the strategies of quiet time and time out as lacking in both ethical acceptability and practical applicability. On the basis of this the authors recommended revisions to the content of the program.

While the research literature has informed and continues to inform the development of SSTP, Probst et al.’s (2010) study does not represent sufficient evidence to modify core program content; data from studies involving multiple informants and empirical evidence of efficacy would be required to do this. Nevertheless, future iterations of program materials will continue to consider issues relating to the accuracy and accessibility of content, as well as data on acceptability, efficacy, and effectiveness.

The perceived acceptability of the content of an intervention is important not only because of issues concerning social validity, but also because such perceptions can impact on the uptake, delivery and (ultimately) the effectiveness of an intervention. The findings of Probst et al., (2010) highlight that there will inevitably be variations in how individuals accept program content. However, it should be noted that it is not always appropriate to alter the intervention itself, as Probst et al., (2010) suggest, to increase the perceived acceptability. If an intervention has been demonstrated to be effective and there is considerable empirical evidence for the specific elements of the intervention in question, then it may be more appropriate to increase perceived acceptability through efforts to decrease professional and parental misunderstanding. To this end, future research could usefully investigate influences on perceptions of content and, in particular, practical strategies to circumvent or overcome barriers to the acceptance of socially valid and empirically supported methods.
Such strategies might impact on the rates at which empirically supported interventions are adopted and implemented with fidelity. Potential strategies could include the provision of high quality information regarding the relevance, efficacy and validity of an intervention or strategy, endorsement of an intervention or strategy by recognised experts, or consumer testimonies regarding the effectiveness and acceptability of an intervention or strategy.

References


Comments on a Study of the Social Validity of the Developmental Disability


Abstract

Results from the recent research literature indicate the urgent need for more intervention outcome studies for Autism Spectrum Disorders (ASD) worldwide, with available interventions commonly being considered a form of “tertiary prevention”. This paper presents a synthesis of two TEACCH-based intervention studies for children and adults with ASD, carried out in Germany: (1) The concept of the “Double ABCX Caregiver Stress-Coping model” (adapted from Pakenham, Samios, & Sofronoff, 2005) having guided our research is outlined and related to tertiary-preventive interventions; (2) based on a broad-category taxonomy adapted from the research literature, and considering recent systematic reviews, three comprehensive intervention approaches are outlined and discussed concerning construct, internal and external validity: (a) “traditional Applied Behavior Analysis (ABA)”, (b) “TEACCH” and (c) “contemporary ABA”; (3) the concept of “structured teaching” being a key component of TEACCH (Schopler, 1997) is outlined briefly. The present synthesis aims at examining the effectiveness of TEACCH based interventions within various social settings. The first study, using a controlled individual-subject design, reports on a social communication training with a 7-year-old girl with autism and intellectual disability living in a residential home. In the second, a small group study, the long-term outcomes of a
TEACCH based intervention in a day care and vocational setting including three adults with ASD are examined. The synthesis of these two studies provides tentative support for the efficacy and effectiveness of TEACCH based interventions across different ages and life settings within the sociocultural context examined. For future evaluation of the TEACCH approach, methodologically sound both individual and group research is needed.

Keywords: Autism Spectrum Disorders; TEACCH; Effectiveness; Evaluation study.
1. Theoretical background and aims of the present study

Autism Spectrum Disorders (ASD) are a group of developmental disabili-
ties defined by (1) qualitative impairments in reciprocal social interac-
tion, (2) qualitative abnormalities in patterns of communication, (3) re-
stricted, stereotyped, repetitive repertory of interests and activities, (4) be-
ginning before the age of three. ASD include (a) “Childhood Autism” (or
“Autistic Disorder”), the most prototypic and severest form among ASD,
(b) “Asperger Syndrome”, and (c) “Pervasive Developmental Disorder -
Not Otherwise Specified” (PDD-NOS) including “atypical autism” (World
Health Organization/WHO, 1992, ICD-10; American Psychiatric Associa-
tion/APA, 2000, DSM-IV-TR; Centers for Disease Control and Prevention
(CDC)/National Center on Birth Defects and Developmental Disabilities,
2010). In addition to the central features of impaired social interaction and
communication, and narrowed interests and activities, a range of other
problems are common, such as temper tantrum, hyperactive, aggressive,
disruptive and self-injuring behaviors. Autism spectrum has been consid-
ered as a group of neurobehavioral disorders showing an estimated cumu-
lative prevalence of 3.7 per thousand (Fombonne, 2005). As yet, primary
prevention interventions for reducing the incidence of ASD or secondary
prevention interventions for reducing the prevalence of ASD are available.
The great majority of individuals with ASD need life-long education and
caregiver support (NRC, 2001; Howlin, 2004). Thus, current interventions
for individuals with ASD imply “tertiary prevention” (or “rehabilitation”),
that aims at (1) preventing disease and “disability progression and atten-
dant suffering” (Wallace, 2010), (2) alleviating and reducing obstructive be-
avioural symptoms, (3) strengthening autonomy and personal responsibil-
ity by fostering social-communicative, cognitive, language, adaptive and
emotional skills, and (4) promoting social participation in the family, class-
room, residential group home, day care setting, workplace, and community,
and thus achieving the best possible level of health and “optimum adapta-
tion” (Schopler, 2005). Tertiary prevention comprises interventions which
address the individual person with autism directly, interventions which fo-
cus on caregivers, and interventions which combine both approaches. Most
programs for tertiary intervention of individuals with ASD put a strong fo-
cus on education, training, supervision, and broad social support of care-
givers (NRC, 2001; Roberts & Prior, 2006; Mesibov & Shea, 2009; Makry-
igianni & Reed, 2010).

1.1 Caregivers’ coping with demands and stresses and the role of ter-
tiary-preventive interventions

Caregivers of children and adults with Autism Spectrum Disorder, such
as parents, teachers and educators frequently face stress in daily life situa-
tions as a result of both the autism-specific symptom pattern of challenging
behaviours and dysfunctional responses of the individual’s environment (Van Bourgondien & Reichle, 1997; Marcus, Kunce, & Schopler, 2005; Probst & Leppert, 2008). According to Marcus et al. (2005), the factors contributing to a unique and high level of stress in caregivers include: (a) diagnostic confusion, frequently caused by professionals’ inadequate communication styles; (b) individual’s uneven and atypical course of development, e.g., discrepancy between verbal and visuospatial abilities; (c) the “can’t versus won’t” dilemma, which is related to the uneven developmental profile, for example, questioning if the individual with autism is unable to respond to a simple verbal request or unwilling to do so; (d) individual’s atypical social communication; (e) individual’s (primarily child’s) typical physical phenotype, which creates expectations of average age-related behaviour in the community, followed by frustration and negative emotions if the individual shows disruptive, embarrassing or other challenging behaviours; (f) social stigmatization of caregivers on common attributional biases, e.g., by attributing stable negative personality traits, such as rigidity, lack of empathy and compulsivity to parents in conjunction with a misinterpreted “broader autism phenotype theory”, or educational inability to teachers; (g) detrimental professional-caregiver relationships, e.g., caused by excessive demands on caregivers through prescribing multiple treatments; (h) fads and unproven treatments disseminated by mass media: e.g., facilitated communication, that creates ungrounded hopes, later mostly followed by deep frustration and hopelessness; (i) vulnerability to simplified claims of treatment sellers like “the only proven therapy claim”. Thus, considering Bronfenbrenner’s ecological model (Huston & Bentley, 2010), caregivers are influenced by various societal contexts of individuals with autism, as its micro-system (e.g. health services), exosystem (e.g. mass media) and macrosystem (e.g. prejudiced attitudes of the culture).

The Double ABCX Model of Family Coping with Stresses (McCubbin & Patterson, 1982) has proven to be beneficial in guiding research and clinical practice in families with a child with ASD (Pakenham, Samios et al., 2005) and can heuristically be used for other caregivers and social environments, such as teachers in classrooms and educators in day care and residential institutions (Figure 1).

The Double ABCX model, an expansion of the former ABCX model, describes how families and other caregiver environments respond to stressors and a crisis associated with caring for or teaching a child with autism under a long-term perspective, whereas the “pure” ABCX model only focuses on the short-term perspective of the actual crisis. The specific temporal perspective in the Double ABCX model is symbolized by the combination of upper-case and lower-case letters (Aa, Bb, Cc, Xx, see Figure 1). The variables of the Double ABCX model include: (1) Aa, the accumulation of (mostly uncountable) demands and stresses in addition to the initial stressor A; (2) Bb, the long-term resources of family/classroom/residential
home/day care setting are for managing a crisis comprising psychological, economical and social resources; (3) Cc, the ongoing process of the family/classroom/residential home/day care’s definition and appraisal of the high-demanding situation (e.g., either perceived as a challenging life task and opportunity for growth or as an unbearable catastrophe); (4) BbCc, conceived as “bridging concept” which includes all coping strategies being applied by the family/classroom/residential home/day care to deal with the challenging situation. Coping (BbCc) brings together cognitive, emotional and behavioral components, so that resources, perceptions and behavioral responses interact in order to restore balance in family, classroom, residential home or day center; (5) Xx, family/classroom/residential home/day center functioning refers to the outcome of parents’, teachers’ and other caregivers’ efforts to achieve a balanced family, classroom and group home life. It includes variables such as care giving quality, social group coherence, and life satisfaction of the group members. As a rule, there is some interplay between all variables described.

To sum up, family, classroom, residential home, and day care functioning (Xx) are dependent not only on the totality of the demands and burdens (Aa) but importantly also on moderator variables, including the caregivers’ psychological, social and material resources (Bb), the interpretation of stressors and demands (Cc), and coping efforts which result from both (BbCc).

Figure 1 - Double ABCX Stress-Coping Caregiver Model (adapted from Pakenham et al., 2005)
As a consequence of their chronically heightened stress profiles, caregivers frequently express an urgent need for professional support (Marcus et al., 2005).

Tertiary prevention within the framework of the Double ABCX-Caregiver Stress-Coping Model (Figure 1) addresses both the needs of individuals with autism by enhancing their skills, competencies and abilities and reducing their obstructive cognitive and behavioral habits, and the caregivers’ needs by strengthening their adaptive resources and enhancing their problem-focused as well as emotion-focused coping abilities. Thus, both caregiver-based and individual-based interventions aim at changing the social systems of family, classroom and remedial institution by modifying cognitions, emotions and behaviors of significant actors interacting in the system.

Roberts and Prior (2006) emphasize in their review that a common core feature of efficient family-centred interventions for ASD has been the establishment of a good relationship between professionals and parents, which includes the competence of health-professionals to enhance the well-being of children with autism and their families by addressing the needs of the entire family. In fact, this conclusion can be generalized to caregivers working in classrooms and remedial institutions with individuals with autism of all ages (Schopler, 2005).

1.2 Comprehensive intervention approaches for ASD based on broad-category taxonomy

Over the last three decades, a range of science-based treatment programs for children and adults with ASD have been developed in the English speaking world. This has been largely the work of university-based groups of scientists focused on pioneers and innovators of autism research and treatment. Using a taxonomy adapted from the recent research literature (Roberts & Prior, 2006; Ospina, Seida, Clark, Karkhaneh, Hartling, Josfold, Vandermeer, & Smith, 2008) for heuristic purpose, the large variety of currently existing intervention programs for ASD can be summarized into three broad categories reflecting their theoretical orientations: (1) Traditional Applied Behavioral Analysis (Lovaas); (2) TEACCH: Treatment and Education of Autistic and related Communication handicapped Children and (3) Contemporary Applied Behavior Analysis:

(1) **Traditional Applied Behavioral Analysis (Lovaas):** The Lovaas program (Lovaas, 2003), developed by Ivar Lovaas at the University of California Los Angeles in the 1960s, is seen as the paradigmatic exponent of the Traditional Applied Behaviour Analysis approach (cf. Prizant & Wetherby, 2005), which is largely based on Skinnerian methods of operant discrimination learning within highly structured, directive, and externally controlled settings. A core feature of Lovaas-based ABA is the “Discrete Trial Format” (Bernard-Opitz, 2007), in which each trial within a series of trials comprises the four elements (1) “Therapist’s Instruction (discriminative stimu-
lus”), (2) “Individual’s Response - where appropriate, prompted by therapist”, (3) “Therapist’s Consequence” - e.g., if response correct, positive reinforcement (e.g. preferred toy or piece of food)”, (4) “Pause” (intertrial interval”) or “Play Break” at the end of a series of trials (Lovaas, 2003, pp. 62-68). Not until recently Lovaas and his research group have been beginning to open the program slightly to concepts that rely more on individual development, visual supports, and strengthening spontaneous behaviours, and to exclude any forms of corporal punishment (Bondy & Frost, 2003; Lovaas, 2003; Lovaas & Eikeseth, 2003).

(2) The TEACCH-program was established by Eric Schopler and Gary Mesibov at the Chapel Hill University of North-Carolina in the late 1960s (Mesibov, Shea, & Schopler, 2006). It is based on a developmental-behavioral and multidisciplinary framework focusing on (a) Structured Teaching in the individual’s daily environment, with visually structured interventions playing an eminent role, and (b) close parent-professional collaboration; (c) comprehensive family, classroom and lifelong community-based service (Schopler, 2005). Autism is seen as a neurobehavioral disorder whose behavioural syndrome is the result of abnormalities in early brain development. A large proportion of autistic children have deficits in auditory-verbal information processing and relatively strong spatial-visual abilities (Tsatsanis, 2005). They also have a need for constant and predictable environments, and daily routines. Based on this knowledge, the TEACCH group created the concept of Structured Teaching (Mesibov & Shea, 2009), which includes components of visually structuring and further structuring components based on developmental, behavioural and cognitive-behavioural theories.

(3) Contemporary Applied Behaviour Analysis: There is a broad group of autism researchers whose approach has been described as contemporary ABA (NRC, 2001; Prizant & Wetherby, 2005; Roberts & Prior, 2006), based essentially on multidisciplinary fields of cognitive, developmental, individual differences and language pathology sciences, and derived developmental-behavioural, social-pragmatic developmental and cognitive-behavioural concepts, with a strong focus on the promotion of “pivotal skills”, such as “self-initiated communication and communicative reciprocity” within naturalistic settings and “emotional regulation” (Prizant & Wetherby, 2005; Roberts & Prior, 2006). This broad group includes Robert Koegel and Lynne Koegel at the University of California, Santa Barbara; Laura Schreibman at the University of San Diego (Schreibman & Koegel, 1996); Vera Bernard-Opitz at the University of California, Irvine (Bernard-Opitz, 2007); and Patricia Howlin at the University of London (Howlin, 2004). However, it is worth noting, that traditional ABA methods, such as discrete trial format interventions are not excluded by a number of exponents of contemporary ABA, but have also been adopted into ASD programs in order to meet some individual needs for highly directive and prescriptive set-
tings, given specific levels of development and behavioural functioning (see Handleman & Harris, 2001; Howlin, 2004; Bernard-Opitz, 2007; Ospina et al., 2008). Finally, it is worth mentioning that there is a conceptual overlap between TEACCH and the contemporary ABA Spectrum as both relying on a broad state-of-the-art multidisciplinary body of research identifying neurological, behavioral, and developmental characteristics of ASD (NRC, 2001; Volkmar, Chawarska, & Klin, 2005; Roberts & Prior, 2006).

1.3 Validity of ASD intervention approaches

For evaluating the overall quality of intervention approaches for ASD, it is necessary to consider three forms of validity: theoretical or construct validity, internal validity, and external validity of the studies on which the respective approach is based. Theoretical validity refers to the degree of integration of state-of-the-art scientific knowledge into the concept of the intervention study, and the degree that an explanation or interpretation developed from a research study fits the data. Internal validity refers to the quality of the study design and includes control for nonspecific factors, such as history, maturation, expectancy, and experimenter bias, making sure that between or within group differences can be attributed at least partially to the influence of the experimental treatment. Thus, providing evidence for a treatment’s efficacy or effectiveness requires some positive level of internal validity. External validity includes control for selection bias, and describes the degree to which the results of the intervention study can be generalized to other individuals, situations, and historical periods (cf. NRC, 2001).

In a series of systematic reviews on interventions for ASD that have been reported, validity and effectiveness issues have been addressed (BCOHTA, 2000; NRC, 2001; Roberts & Prior, 2006; Singer, Ethridge, & Aldana, 2007; Ospina et al., 2008; Rogers & Vismara, 2008; Speckley & Boyd, 2009; Eldevik, Hastings, Hughes, Jahr, Eikeseth, & Cross, 2009; Mesibov & Shea, 2009; Reichow & Volkmar, 2009; Reichow & Wolery, 2009; Makrygianni & Reed, 2010; Virués-Ortega, 2010).

1.3.1 Theoretical validity

(a) Considering the traditional ABA approach, there are some factors that weaken the theoretical validity. Firstly, also more recent studies of Lovaas and colleagues (Eikeseth, Smith, Jahr, & Eldevik, 2002; Lovaas, 2003; Sallows & Graupner, 2005) show a strong preponderance of “operant conditioning principles”, “discrete trial training” and “contingency management”, and thus indicating some lack of synthesizing current knowledge from cognitive, developmental and clinical disciplines sufficiently (NCR, 2001; Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006). Secondly, Lovaas’s claim to enable children with autism to achieve “normal functioning” (BCOHTA, 2000; Lovaas, 2003) is in contradiction to the current thinking of interdisciplinary research. In a systematic review from the University of British Columbia (Canada) Lovaas and col-
leagues are criticised for having not limited their effectiveness claims to achieving substantial developmental gains but having “permitted, and even fostered” the notion of normal functioning for as many as a half a given population of children with autism “throughout their published literature” (BCOHTA, 2000). Overall, because of these and further conceptual biases (cf. Roberts & Prior, 2006) the theoretical validity of the traditional ABA approach is considered to be severely limited.

(b) The theoretical validity of the TEACCH approach ought to be evaluated as high because interdisciplinary state-of-the-art knowledge has been taken into consideration, such as concepts of social-cognitive learning, individual differences (see “culture of autism”, Mesibov & Shea, 2009), neuropsychology, developmental psycholinguistics, cognitive-developmental, and clinical family psychology (NRC, 2001; Mesibov et al., 2006).

(c) Similarly, considering well-known comprehensive programs for ASD to be subsumed under the umbrella term of contemporary ABA (Roberts & Prior, 2006; Ospina et al., 2008), such as the Pivotal Response Training (Schreibman & Koegel, 1996), the Structured Teaching and Experience-based Program (STEP, Bernard-Opitz, 2007), and the Social Communication Emotional Regulation Transactional Support program (SCERTS, Prizant et al., 2006), there is much evidence for high theoretical validity as current interdisciplinary knowledge as on social cognition, social-emotional abilities, natural language strategies, alternative communication, and intrinsic motivation has been integrated systematically and applied for serving individuals with autism.

1.3.2 Internal validity and effectiveness

(a) Traditional ABA: Concerning the effectiveness\(^5\) mixed findings from various systematic reviews on interventions for children with autism have been reported. All effectiveness results which have been analyzed are based on group comparisons between traditional ABA and standard/ eclectic treatment or low-intensity traditional ABA treatment. Any comparative studies including comparisons to alternative comprehensive programs, such as TEACCH or contemporary ABA programs do not exist as yet.

Various meta-analyses (Ospina et al., 2008; Eldevik et al., 2009; Reichow & Wolery, 2009; Virués-Ortega, 2010; Makrygianni & Reed, 2010) including three (Ospina et al., 2008) to eleven controlled clinical studies (Makrygianni & Reed, 2010), indicated effect sizes in the “medium” to “large” range\(^6\)

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\(^5\) In this article, we use “effectiveness” in the broad sense as comprising both “efficacy” referring to effects of an intervention in controlled laboratory settings (Kazdin & Weisz, 2003) and “effectiveness” (in the narrow sense) referring to effects in real-life clinical practice (ibid., NRC, 2001).

\(^6\) See effect size categorization according to Cohen, as cited in Ospina et al. (2008), where 0.2 indicates a small effect, 0.5 a medium effect and 0.8 a large effect size.
for intellectual functioning, language and adaptive behavior in favour of traditional ABA high intensity treatment (usually 25-35 h per week over 2-3 years). The results of a previous meta-analysis of the effects of ASD programs including the “Lovaas” approach (Probst, 2001) are congruent with the findings of the current analyses. In contrast, Spreckley and Boyd (2009) reported from their meta-analysis, based on four controlled studies only non-significant “small” effect sizes for intellectual, language and adaptive behavior outcomes. Correspondingly, these reviews resulted also in mixed conclusions. Eldevik et al. (2009), Virués-Ortega (2010), Makrygianni and Reed (2010), and Reichow and Wolery (2009) evaluated traditional ABA unanimously positively as promising, effective, and superior to eclectic control programs, whereas Spreckley and Boyd (2009) concluded that there is no evidence for significant additional benefit of traditional ABA over standard care for intellectual functioning, receptive and expressive language, and adaptive behaviour. These authors assumed that the great majority of children examined showed progress caused by natural development rather than intervention. Notably, Ospina et al. (2008) have interpreted their meta-analytic findings showing multiple improvements in favour of traditional ABA with marked reservation. They summarized sceptically that this approach may improve some core symptoms of ASD, however with the limitation that these findings are based on pooling of only a few, methodologically weak studies, and consequently there is no definite evidence suggesting superiority of this approach over other interventions (Ospina et al., 2008). There are also systematic narrative reviews addressing the effectiveness of traditional ABA. In their review on comprehensive treatments for early autism, based largely on four controlled studies, Roberts and Vismara (2008) conclude, that Lovaas’s intervention approach meets the Chambless et al. criteria (Chambless & Hollon, as cited in Roberts & Vismara, 2008) for “probably efficacious” (Roberts & Vismara, 2008, p. 30) concerning the overall outcomes including intelligence (IQ), behavioral outcomes, adaptive skills, and language skills. The authors evaluate the approach as “well-established” with regard to improving intellectual functioning in young children with ASD (loc. cit., p. 25). In this context, it is worth mentioning that there is an ongoing controversy about to which extent the improvements in IQ are influenced by measurement instrument variation and related methodological problems (Roberts & Prior, 2006). Both the review of BCOHT (2000) and the review of Roberts & Prior (2006) emphasize consistently that there is strong evidence for traditional ABA improving and alleviating symptoms, however no evidence for recovery and cure. Roberts and Prior (2006) assume that, primarily due to claims relating to “recovery”, “exclusivity” (i.e. superiority), and “intensity”, the Lovaas approach is “among the most controversial interventions” for ASD.

Regarding the internal validity of studies on the traditional ABA method, factors supporting the internal validity include: (a) the existence of
a total of 7 controlled clinical trials, among them 2 randomized controlled studies (Ospina et al., 2008, table 1, under “discrete trial” and “UCLA/Lo-vaas), reflecting a “unique high level of scrutiny” compared to all other approaches (Roberts & Prior, 2006), (2) comprehensive manualization of the treatment program (Lovaas, 2003), and (3) use of standardized multimodal outcome measures. Factors threatening internal validity include: (1) lack of controlled studies including comparison groups based on TEACCH or equivalent programs of temporary ABA, rather than weakly defined eclectic treatment or non-treatment groups (Eldevic et al., 2009), (2) lack of cohort studies or within-group studies addressing classroom functioning in preschools and schools, (3) interpretational biases, in raising claims deduced from research studies that are not supported by empirical evidence, such as recovery-and-normalization-claims, the alone-proven-method-and-superior-to-others-claim, and the high-intensity-intervention-for-all-children-and-families claim (cf. Roberts & Prior, 2006), and (4) lack of external evaluators being outside the traditional ABA researcher network.

(b) **TEACCH approach:** Concerning the effectiveness, evaluation is largely based on five controlled studies as documented in the narrative review of Mesibov and Shea (2009). (1) In the Bristol et al. study (as cited in Mesibov & Shea, 2009), the low-intensity TEACCH-based parent-child home program was superior to the no-treatment condition for reducing depression in mothers, indicated by a follow-up effect size in the medium range (Probst, 2001; Singer et al., 2007). (2) In the Ozonoff and Catheart study (as cited in Mesibov & Shea, 2009), the group who received the low-intensity home-based TEACCH program improved significantly more in child developmental outcomes than the eclectic-standard care control group, with an single study effect size scoring in the “low” range (Probst, 2001). In addition, in the metaanalytic review of Ospina et al. (2008), the Ozonoff and Catheart study was pooled with another TEACCH-based study published by Tsang et al. (as cited in Ospina et al., 2008), which, however, shows severe methodological flaws, so that the resulting pooled effect sizes reported for two developmental outcomes, scoring in the “low” and “zero” range, are difficult to interpret. (3) In the randomized controlled study of Welterlin (2009) with a wait list comparison group, the experimental group who received the low-intensity parent-child home-based TEACCH program improved significantly more both in child and parent outcomes. (4) In the Panerai, Zingale, Trubia, Finocchiaro, Zucarello, Ferrari, & Elia (2009) study (as cited in Mesibov & Shea, 2009), a moderate-intensity centre-based TEACCH parent training was significantly superior to a standard special educational treatment in terms of both child behavioural and developmental outcomes. (5) In the Bourgondien et al. study (as cited in Mesibov & Shea, 2009), the TEACCH-based residential program for adults was superior to residential and family standard care in terms of adult behavioral adaptation and parent satisfaction.
In their narrative review, Roberts and Prior (2006) concluded that the results of a small number of studies indicated positive outcomes for children affected by the TEACCH program. According to Ospina et al. (2008), individual evaluative studies consistently report significant findings for a variety of outcomes. Overall, however, Ospina et al. (2008) concluded that the evidence to support the effectiveness of “integrative programs” (comprising TEACCH and social skills programs) is limited.

Positive indicators of internal validity include (1) the partial manualization of the TEACCH program (Watson, Lord, Schaffer, & Schopler, 1989; Faherty & Hearsay, 1996; Mesibov & Howley, 2003) and (2) the use of real-life outcomes reflecting child-parent interactions. Negative indicators include: (1) a lack of prospective cohort studies, pre-post one-group studies, and controlled single-subject studies describing the effects of high intensity (about 25-30 h per week over 2-3 years) TEACCH-based interventions in preschool classrooms; (2) broad lack of prospective cohort studies, pre-post studies, and controlled single-subject studies examining the effects of Teach-based programs in categorical and inclusion classrooms, and residential and workshop settings; (3) lack of controlled clinical studies comparing the effects of intensive and comprehensive TEACCH interventions with corresponding equivalent interventions of other approaches, such as the traditional ABA-approach of Lovaas; (4) the broad lack of controlled studies addressing the effects of low-to-moderate-intensity family and parent interventions characteristic for the TEACCH approach; and (5) a tendency to undervalue evidence-based intervention research methods as recommended in the literature (NRC, 2001; Ospina et al., 2008) and instead primarily focus on “good clinical or service programs”, “habilitation effort” (Schopler, 2005), “clinical expertise” and “real world practice” (Mesibov & Shea, 2009).

(c) Contemporary-ABA: According to Rogers and Vismara (2008), the Pivotal Response Training (PRT) program developed by Schreibman and Koege (1996) addressing the enhancement of imitation, language, communication and play skills in as natural as possible environments, shows the best effectiveness evidence within the temporary ABA category. Based on multiple single-subject studies, it meets the Chambless and Hollon criterion of a “probably efficacious” intervention (ibd.). Correspondingly, in the meta-analysis of Probst (2001), a pooled “large” effect size of 1.2, based on two controlled PRT parent training studies, was reported for child-parent interaction in favour of PTR, compared to discrete trial-based parent training. Additionally, Ospina et al. (2008) report some evidence that PRT may be beneficial for communication and social interaction. In the review of Rogers and Vismara (2008) three further studies, based on RCT designs, are reported, which meet the “possibly efficacious” criterion of Chambless and Hollon: a Canadian program presented by Jocelyn et al. (as cited in Rogers & Vismara, 2008) comprising a child day care worker and parent training intervention resulting in positive caretaker and child outcomes; a
British program, evaluated by Drew et al. (as cited in Rogers & Vismara, 2008) addressing “pragmatic language intervention” in addition to community standard care; and a British program presented by Aldred et al. (as cited in Rogers & Vismara, 2008) including a home-based, parent-delivered developmental intervention, with parents having been trained in pragmatics of social communication and behavior management. Finally, the Scottish Centre for Autism Preschool Treatment program, presented by Salt et al. (as cited Rogers & Vismara, 2009) in a controlled study comprising parent-child small group interventions addressing imitation, joint attention, social reciprocity and play, was evaluated positively as “important initial finding” of a “developmental treatment approach”, however not yet meeting the “possibly efficacious” level (ibid.). In addition to Rogers and Vismara (2008), programs of the contemporary behavioral approach have been appraised positively by several reviewers, such as NRC (2001) as demonstrating effectiveness for speech, language and communication, and similarly also by Roberts and Prior (2006), and Singer et al. (2007). Further, Ospina et al. (2008) reported some evidence for significant improvements in various child domains and parent’s mental health for programs including cognitive behaviour therapy. Finally, Reichow and Volkmar (2009) in their review of social skills interventions, reported “established evidence-based practice” for social skill group programs, and “promising evidence-based practice” for video modelling programs, based on the evaluation category system of Reichow, Volkmar and Cicchetti (as cited ibid.). Presenting a more reserved and sceptical side, Ospina et al. (2008) concluded in sum, that the evidence supporting the use of contemporary ABA approaches is variable and there is no evidence of the superiority of one program over the other, and there is also limited evidence for “developmental interventions”.

To sum up, factors positively influencing the internal validity of contemporary ABA comprise: (1) use of controlled trial designs and (2) use of multiple measures including real-life outcomes. Negative factors include: (1) broad lack of replication studies, (2) lack of synthesis of targets, curricula, and measures, (3) lack of comparison and long-term studies, and (4) lack of manualization of treatments.

1.3.3 External validity (a) Traditional ABA: External validity is positively influenced by: (1) completion of multi-site clinical trials across different countries in North-America and Europe and (2) international provision of trainings for professionals and parents. Negative factors include: (1) lack of program flexibility concerning the prescribed high intensity of the early intervention program with a magnitude of at least 30 hr/week over two and more years for all children and families, which means a major burden for many families, and is also a problematic level of input for service providers in the communities (Spreckley & Boyd, 2009), and (2) setting false hopes and creating confusion in parents, individuals with ASD, and professionals...
by exaggerated claims for treatment success in form of “recovery” or “normalization” (Marcus et al., 2005).

(b) **TEACCH:** Positive indicators of external validity include the following: (1) Provision of a federal state-wide service in North-Carolina (USA) covering all ages from early childhood to late adulthood, and life settings from family to community life. (2) Provision of low-threshold continuum of parent and family support being mindful of different resources and abilities of parents and other family members. (3) Systematic training of caregivers in methods of *structured teaching* contributing to the generalization of the autistic person’s learning processes into different life environments (Schopler, 2005). (4) Provision of a continuum of TEACCH-assisted educational settings considering various individual needs, ranging from special education to inclusive general education classrooms offering graded levels of assistance for the child with autism. (5) Broad social acceptance of the program’s goals, methods and effects by caregivers, individuals treated, and the community (Schopler & Mesibov, 2000; Probst, Konstantareas, Leppert, Panerai, & Rampton, 2008), which constitutes “social validity” (Foster & Mash, 1999), a core aspect of external validity. Factors adding to the social validity of the TEACCH program include the avoidance of excessive technical-behavioural terminology, which many professionals and families are opposed to (Probst, Glen Spreitz, & Jung, 2010), and the “holistic orientation” (Schopler, 2005), seeing the whole individual within the context of a unique social group (e.g., family) rather than under the narrow perspective of a specialized discipline. (6) Focus on the “generalist” model of treatment that avoids splitting the treatment into many specialized services, acknowledged, in particular, by the health systems of developing countries. (7) Implementation of TEACCH programs in a number of countries North America, Asia, Australasia, and Europe (NRC, 2001; Mesibov & Shea, 2009) including adaptation to different social and family contexts as, for example, in Italy (Roberts & Prior, 2006). (8) Finally, on an international scale, provision of training programs for professionals in weeklong workshops with hands-on component. Factors negatively affecting external validity include (1) small sample sizes and (2) broad lack of replication studies.

(c) **Contemporary ABA:** The *external validity* is supported (1) by program flexibility taking into account variety of individual, family and community resources and (2) high social acceptance of curriculum aims of enhancing social communication in naturalistic settings and strengthening pivot competencies of motivation, attention and self-management. The external validity is threatened by (1) small sample sizes, (2) lack of replication studies, and (3) lack of program dissemination across various countries.

### 1.4 Overall conclusions from validity analysis
Based on the preceding analysis of comprehensive reviews, the following overall conclusions can be drawn.
There are numerous inconsistencies across the various meta-analyses and narrative reviews which have been analyzed. Possible reasons for this include firstly the use of varying methods of study selection, varying standards of quality assessment, and varying methods of analysis and presentation of results by different reviewers and secondly some susceptibility to the Rosenthal effect, according to which reviewers’ beliefs, biases, and expectations influence the phenomenon of investigation (Makrygianni & Reed, 2010).

The traditional ABA approach is characterized by substantial limitations to theoretical and moderate limitations to external validity. The internal validity is moderately limited, mainly due to methodological and interpretational biases. Lovaas’ and his colleagues’ excessive claims like that of recovery and normalization might be founded in their belief in radical environmentalism as taught by Burrhus F. Skinner, which presupposes that man is largely controlled by his environment and that “it is an environment largely of his own making” (Skinner, 1971, p. 215). Despite these limitations, the reviews provide sufficient evidence for substantial effectiveness across developmental and behavioural outcomes for preschool children with autism, at least in the low-to-medium effect size range.

The TEACCH approach has adequate theoretical validity and largely adequate external validity. The internal validity is moderately limited, in particular by the broad lack of controlled single subject and group studies in TEACCH-based preschools and schools. Based on the reviews, there is sufficient evidence for substantial effectiveness for low-to-medium intensity TEACCH interventions in families, across child developmental and behavioural outcomes and parental stress measures, at least in the low-to-medium effect size range.

The contemporary ABA approach is characterized by adequate theoretical validity, moderate limitations to external validity, mainly due to the broad lack of replication studies, and moderate limitations to internal validity, in particular due to the lack of controlled group studies and manualization of programs. Regarding the Pivotal Response Training, the reviews provide substantial evidence for effectiveness across child and parent outcomes. Further, there is some promising but mixed and tentative evidence for a number of related programs presented in this category.

All three approaches show some lack of comparison studies addressing an alternative comprehensive program instead of eclectic standard care programs. Thus, currently no conclusions about relative effectiveness or “the most effective” intervention approach (Roberts & Prior, 2006) can be drawn (cf. Dawson & Osterling, 1997; NRC, 2001; Ospina et al., 2008). However, using the criterion of an overall validity assessment, based on the aggregation of theoretical, internal, and external validity ratings as pointed out above, TEACCH is superior to the other two approaches. Hence, we considered the TEACCH program the currently “best practice” approach.
available and thus suitable for being tested in the German mental health care setting.

1.5 Concept of structured teaching

The concept of “structured teaching”, which is considered to be a key feature of the TEACCH program is briefly outlined. Table 1 summarizes the components and subcomponents of structured teaching.

Table 1 - Key features of Structured Teaching

<table>
<thead>
<tr>
<th>Components and subcomponents of Structured Teaching</th>
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<tbody>
<tr>
<td>(A) <strong>Visually Structuring</strong>: Providing Visual Structure for the individual’s daily environment (Schopler, Mesibov, &amp; Hearsey, 1995; Mesibov &amp; Howley, 2003) is a central component of <strong>Structured Teaching</strong>. Interventions based on Visually Structuring include the subcomponents:</td>
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<tr>
<td>(1) <strong>Physical Organization</strong>, for example, visually cued areas and boundaries for specific activities and objects;</td>
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<td>(2) <strong>Schedules</strong>, e.g., schemes on a daily or weekly basis, explaining which activity occurs next and in what sequence by means of visual, verbal or nonverbal symbols;</td>
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<td>(3) <strong>Work and Learning System</strong>, i.e. informing children of what is expected of them in independent work activities, assisted learning activities, and daily living and leisure activities, again by means of visualized nonverbal or verbal information;</td>
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<tr>
<td>(4) <strong>Task Organization</strong>, which means selection and arrangements of visual materials used in various work systems in order to provide clear instructions to the child for completing the task as independently as possible;</td>
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<td>(5) <strong>Behavioural Routines</strong>, which imply visually structured and organized sequences of goal-directed behaviours, e.g., doing pre-academic tasks in a specified order.</td>
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<td>(B) <strong>Further Components of Structured Teaching</strong> include:</td>
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<td>(6) <strong>Concise Verbal and Nonverbal Directions/ Instructions</strong>;</td>
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<tr>
<td>(7) <strong>Behavioural Prompts</strong>;</td>
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<tr>
<td>(8) <strong>Consequence-Based Interventions</strong> (Bregman, Zager, &amp; Gerditz, 2005) including (a) strategies of reinforcement emphasizing natural consequences and self-reinforcement and (b) methods of mild negative consequences, such as admonishing or reprimanding, whereas more restrictive methods, such as exclusionary and isolating time-out (cf. Probst et al., 2010) have not been established in more recent versions of the TEACCH program (see Mesibov et al., 2006)</td>
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<tr>
<td>(9) <strong>Behaviour Shaping</strong> methods by means of gradual approximation towards target behaviours;</td>
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<td>(10) Additional cognitive-behavioural interventions, such as <strong>Behavioural Contract</strong> methods, or <strong>Stress Management Training</strong> (Mesibov et al., 2006);</td>
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<tr>
<td>(11) <strong>Skill Enhancement Training</strong> methods (Bregman et al., 2005) for daily living, (pre)academic, social-communicative, and self-management skills (Schopler, 1994, 1997; Quill, 2000; for functional communication training components, see Watson et al., 1989), based on the combined use of “antecedent” (e.g., <strong>Visually Structuring</strong>, <strong>Giving Directions</strong>, <strong>Prompting</strong>) and <strong>Consequence-Based Interventions</strong> (Bregman et al., 2005) (e.g., enabling individuals to use self-reinforcement).</td>
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</table>
1.6 Research context and aims of the present synthesis

While a number of TEACCH-based programs have been implemented in German-speaking countries currently (Degner & Müller, 2008), there is a broad lack of formal evaluation of this intervention. However, evidence for effectiveness and social acceptance (“social validity”; Foster & Mash, 1999) is urgently needed for improving the quality of patient care (Kazdin, 2008) and supporting decision making of health care providers and policymakers. Thus, we started a multi-step research program addressing the effectiveness of TEACCH-based interventions for children and adults with ASD including various target persons and settings at the Department of Psychology of the University of Hamburg. In developing and implementing research strategies we were guided by: (a) recommendations of NRC (2001) for combining single subject and group studies, (b) guidelines of Dingfelder and Mandell (2010) for diffusion of novel interventions in public mental health and education systems recommending a stepwise strategy, beginning with more explorative and pilot-like single-subject and within-group studies within real-life clinical and educational settings, and continuing in following phases with more controlled studies, and (c) recommendations of Reichow and Volkmar (2009) highlighting the need for studies involving also adolescent and adult participants with autism and using outcome measures sensitive for meaningful, clinically and socially valid changes by interventions.

In total, six studies were conducted, of which the first four, reported on other places, are outlined only very briefly in the following, the last two sharing common methodological features are reported in the present synthesis:

The first study addressed the effectiveness of a three-full day, centre-based education and skills parent group training with 23 younger school-aged children and resulted in positive parent-reported child and parent outcomes (Probst & Leppert, 2007; Probst, 2010). The second, a descriptive case study (Probst, 2010), examined the effectiveness of a medium-intensity TEACCH-based home child-parent program with a five-year-old boy over two years and overall resulted in positive parent outcomes and beneficial child outcomes across family and classroom settings. The third, a within group study addressed the effectiveness of a three-full day centre-based special education teacher skills training including an classroom teacher support component, involving 10 young school-aged children and 10 teachers, showing teacher-reported significant child behaviour and teacher stress-reduction outcomes (Probst & Leppert, 2007, 2008). In the fourth, a descriptive-quantitative observational study, the effectiveness of a centre-based low-intensity social communication enhancement small group program which included in addition to the small group component a one-to-one child-therapist component and a parent tutorial component (Probst, 2010) involving two older school-aged children and one young adult, was examined with results providing tentative evidence for improved social-communicative behaviors within programmed high- and low-structured play activities.
The fifth study, an experimental single subject study addressed the effectiveness of a low intensity social communication training with a 7-year-old girl living in a remedial residential home. The outcomes are reported in section 3.1. The sixth study, a retrospective quantitative small group study, the effectiveness of a long-term TEACCH-based intervention in a residential and vocational setting was examined. The results are reported in section 3.2. Both studies have been included into the present synthesis because they share common features of design, measures, and outcome analysis. Further, they address target participants and settings frequently neglected in research for ASD (Reichow & Volkmar, 2009; NRC, 2010).

2. Methods of synthesis

Both studies reported were carried out by the ASD research unit of the Department of Psychology at the University of Hamburg between 2007-2008. In total, four persons with ASD (one child, three adults) participated, of which three had a diagnosis of child autism, and one a diagnosis of PDD-NOS including atypical autism.

One of the authors (P.P.) had formal training in the TEACCH approach (5-day intensive training). The other persons who participated in the two studies (J.M. and F.J.) completed internships of 500 or more hours duration at the ASD research unit (University of Hamburg) which included training in TEACCH methods as well as clinical-educational practice with children with ASD and their parents. The studies were supervised by the first author.

The evaluative instruments used in the reported studies included standardized tests, standardized caretaker questionnaires, semi-structured interviews, and behavioural observation measures.

3. Studies

The reports on the two studies are structured into (1) theoretical background and aims of the study, (2) methods, (3) results, and (4) conclusions. The overall conclusions for the synthesis are discussed in section 4.

3.1 Outcomes of a controlled single-subject social communication training study with a 7-year-old girl with autism and intellectual disability living in a residential home

3.1.1 Theoretical background and aims of the study Interventions in children with ASD focus on enhancement of adaptive abilities, in particular social communicative and daily living skills (Schopler, 1997). The concept of
“social-communicative” refers to the individual’s ability to understand social events and to participate as a competent and cooperative partner in social activities using both verbal and nonverbal skills (Prizant et al., 2006, p. 315). “Daily living skills” include domestic activities like personal hygiene, dressing, cleaning up and cetera. Enhancing these skills on the one hand and simultaneously delivering antecedent adjustments to the child’s environment on the other hand are likely to decrease behaviour problems (Schopler, 1995; Bregman et al., 2005). The TEACCH-approach uses both components and has proven to be effective in treating children with autism both in families and residential settings (Schopler, 1997; Mesibov & Shea, 2009). However, there is a worldwide lack of formal evaluation of TEACCH-based interventions, for children in residential homes.

Aims: The aim of this single-case study was to evaluate a TEACCH-based intervention in a 7 year old girl with childhood autism. Treatment addressed massive behaviour problems and focused on enhancing social communicative skills. The program was implemented within remedial residential care.

3.1.2 Methods

3.1.2.1 PARTICIPANT The participant of the study was L, a 7-year old girl with childhood autism and with severe mental retardation. Diagnosis of autism was substantiated by results significantly above the cut-off in the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994; German version Bölte, Ruhl, Schmötzer, & Poustka, 2006) and the Autism Diagnostic Observation Schedule (ADOS, Module 1; Lord, Rutter, DiLavore, & Risi, 2001; German version: Rühl, Bölte, Feineis-Matthews, & Poustka, 2004) as well as the result of “severe autism” in the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1993). Further, L showed a very low-level spontaneous communication rate, as assessed by behavioural observation (see Watson et al., 1989). The Psychoeducational Profile-Revised (PEP-R; Schopler, Reichler, Bashford, Lansing, & Markus, 1990; German version: 2000) revealed a developmental age of 15 months. At the time of intervention L had been living in a remedial residential group for about two years, with sporadic contact to her mother on weekends. Caregivers reported massive behaviour problems (e.g., aggressive behaviour, self-injurious behaviour, problems in hygiene, Pica) and very low social-communicative competencies, characterized most notably by restricted and stereotyped solitary activities and aggressive reactions in socially demanding situations. Contingent on the caregiver/child ratio (between 2 and 3 caregivers, depending on morning and day shift, for 10 residents) L’s behaviour problems became unbearable and her continuing taking part in the group was in danger of being compromised.

Therefore, the following aims of the study were defined: 1) reduction of behaviour problems, 2) enhancement of social-communicative abilities: au-
tonomous handling of her picture schedule and her choice-board, 3) general improvement on developmental functioning, 4) teaching a disability concept to caregivers and parents in terms of functional analysis and explanation of behaviour problems.

3.1.2.2 Description of Intervention Conceptual framework: The intervention program is mainly based on principles of Structured Teaching (Schopler et al., 1995) including these elements: (a) Visualized Structure of Space and Objects (Segregation of work- and recreation-space, e.g., a desk, identified via picture card as “work space”), (b) a Picture Schedule for program activities which contains the elements “work card” and “recreation card” in order to visualize the structure of each session and a Choice-Board which contains several picture cards representing recreation activities in order to increase the ability of social interaction, (c) Visualized Work System (tasks to do on left side of the desk, a finish box to put the processed materials in on the right side of the desk) and visually supported tasks (e.g., coloured materials in sorting tasks), (d) Concise Verbal Instructions, (e) guiding through Physical, Gestural and Verbal Prompts, especially in teaching the handling of the picture schedule and choice-board, (f) Verbal and Nonverbal Reinforcements (e.g., praise, plaudits, small pieces of salt sticks), and (g) Mild Forms of Punishment, such as admonitions or strict “No” in order to stop challenging behaviours. Following, Watson et al. (1989) the use of natural consequences was of particular importance in order to enhance the participants comprehension of the potential power of communication (e.g., L. gets her headphones in exchange for the music –picture card of her choice board).

The selection of exercises for the “work period”, a range of assembling, sorting and fine motor skills tasks, based on indications of the PEP-R.

L’s picture schedule showed in a vertical order (from top to bottom) her picture and name card, followed by the work card, which led her to her desk where a respective twin card was installed. After work-phase, L picked her recreation card from her desk, which led her to her choice board and she put the card beside the respective twin card. The choice board showed again her picture and name card on top and two picture exchange cards beneath, whereas one represents the activity “listening to music” and the other “waving a rubber glove” (arranged from left to right).

3.1.2.3 Measures a) Behavior Problems Inventory (BPI): The BPI by Rohjan, Matson, Lott, Esbensen, and Smalls (2001) was used in the German adaptation by Steinhausen (2005) to attain measures of the participant’s problem behaviour. It consists of 52 items scored on a 5-point frequency scale (0 = never, 1 = monthly, 2 = weekly, 3 = daily, 4 = hourly). The scale provides a Full Scale Score (internal consistency (Cronbach’s ) = .72) as well as scores for three subscales Self-Injurious Behaviour (internal consistency = .48), Stereotypied Behaviour (internal consistency = .68), and Aggressive/Destructive Behaviour (internal consistency = .86). As with Rohjan
et al. (2001) the severity data were excluded from this paper because of the high correlations with the frequency scales and hence become redundant.

b) Structured video based behaviour observation of the amount of help in using the schedule and choice-board: Target behaviours for both fields were defined. “Use of the picture schedule” comprised the steps: (1) she walks to her schedule; (2) she picks the “work card”; (3) she gets to her desk; (4) she pins the work-card next to the twin card on her desk; (5) she takes the “work card” and gets back to her schedule; (6) she puts the work-card in to the “finish envelope”; (7) she picks the “smiley card” (recreation). “Handling of the choice boards” followed the steps: (1) she pins the “smiley card” next to the twin card on the choice board; (2) she picks an activity symbol card; (3) she passes the card over to the therapist / caregiver. Each step was scored on a 4-point assistance scale (3 = needs direct physical assistance / prompt, e.g., hand-over-hand assistance; 2 = needs reduced physical assistance, e.g., less frequent hand-over-hand guidance; 1 = needs gestural / verbal prompts, e.g., pointing at the card next to be picked; 0 = needs no assistance).

c) Psychoeducational Profile – Revised (PEP-R): The PEP-R (Schopler et al., 2000) provides information on developmental functioning in the areas of imitation, perception, motor, eye-hand integration, cognitive performance, and cognitive verbal skills. An estimated developmental age can be indicated.

d) Informal conversations/interviews with caregivers and the mother: Over the course of intervention repeated informal conversations with caregivers were held regarding the effects of intervention on L’s behaviour and general concerns with regard to the program. In addition, telephone conversations concerning the course of the intervention and L in general were held with the mother at fortnightly intervals.

3.1.2.4 Procedure Each session was subdivided into an up to three times reoccurring sequence of “Work period” (e.g., doing sorting and assembling tasks) and “recreation period” (“Use of the choice board”, e.g., choosing the “music card” in order to hear music as a reward). Intervention spanned 12 sessions (each 45-60 minutes) in 2 months.

3.1.2.5 Data Analysis Quantitative data were analyzed with Statistical Package for the Social Sciences (SPSS), version 15. Means for behaviour observation data (see 3.1.2.3 b) were computed for each session and visually analysed (Kazdin, 1982; Julius, Schlosser, & Goetze, 2000).

The qualitative analysis of verbal data was realized by methods described in the “Qualitative Content Analysis” by Mayring (2000).

The Reliable Change Index (RCI, Jacobson & Truax, 1991) was used to yield possible pre-post-gains. The RCI is calculated by dividing the difference of the participant’s post-test and pre-test score through the standard error of difference of the two test scores. The standard error of difference “describes the spread of the distribution of change scores that would be ex-
pected if no actual change had occurred. An RC[I] larger than 1.96 would be unlikely to occur \((p < .05)\) without actual change” (Jacobson & Truax, 1991, p. 14).

3.1.3 Results Changes in behaviour problems: Table 2 shows the results (means of 4 caregivers; integer values) on the BPI scales at the time of baseline assessment (“pre”) and the final assessment (“post”). The Full Scale Score decreased from 79 to 66. There was a reduction in all three sub-scales, though only minimally for Self-injurious behaviour (see Table 2). Still the scores are widely over the mean in an intellectual disability reference group of about 100 individuals in North America (Gonzales, Dixon, Rojahn, Esbense, Matson, Terlong, & Smith, 2009). The RCI (Jacobson & Truax, 1991) based on standard deviations and internal consistencies of that sample were computed for each scale. Although the RCI values were not statistically significant all reflected pre-post gains in the predicted way.

Critical incidents: There were three findings considered to be of special interest for every day life in the group home: Item “Pica” (craving for something not normally regarded as nutritive, e.g., dirt) reduced from “daily” to “weekly” occurrence. The items “Biting” and “Cruel” (e.g., taking something away from others) reduced from a “weekly” to “monthly” occurrence.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Pre</th>
<th>Post</th>
<th>RCI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Injurious Behaviour</td>
<td>14</td>
<td>13</td>
<td>0.24</td>
</tr>
<tr>
<td>Stereotyped Behaviour</td>
<td>51</td>
<td>41</td>
<td>1.60</td>
</tr>
<tr>
<td>Aggressive/Destructive Behaviour</td>
<td>15</td>
<td>12</td>
<td>0.85</td>
</tr>
<tr>
<td>Full Scale</td>
<td>79</td>
<td>66</td>
<td>1.33</td>
</tr>
</tbody>
</table>

Table 2 - Results of the BPI in pre- and post-assessment

Note: RCI=Reliable Change Index.

\* Means across 4 caregivers, rounded to integers

\* All values reported indicate improvement but are not significant \((p > 0.05)\)

Enhancement of social communicative abilities: Autonomous handling of her picture schedule and her choice board: Figure 2 shows the results of the video-based behaviour observation concerning the amount of help in using the schedule and choice board. The respective points of data indicate the amount of assistance needed per session (each session consisted of 1 to 4 sub-sessions in handling the schedule/choice board).
Schedule: Session 1 served as baseline. Due to technical reasons, no formal video-based pre-treatment baseline measure was possible. According to informal interviews with caregivers and teachers at school, L had had no prior experience in handling visual schedules or the principal of picture-based communication. The curve (Figure 2) shows a decreased amount of help needed already in session 2. In 10 out of the 11 following sessions (92%) the amount of help needed was below the baseline. The curve shows a consistent trend to an autonomous handling of the schedule. In session 8 the needed help was above the baseline. In that session only one sub-session took place and the session had to be aborted subsequently because of unacceptable temperature in the client’s room.

Choice-board: Session 1 served as baseline. The curve reveals that the amount of help needed was above the baseline in all the subsequent sessions (Figure 2). Up to session 7 the curve showed a steady learning progress in handling the choice-board. The increased amount of help needed in session 8 reflected the unacceptable temperature in the clients’ room.

Legend: The curves indicate the course of assistance needed in handling the schedule/choice board over the 12 sessions of intervention. Data points indicate the mean amount of needed assistance per session (each session consisted of 1 to 4 sub-sessions). Session 1 is regarded as “Baseline”.

Range of Value for “Amount of assistance”: 3 = needs direct physical; 2 = needs reduced physical assistance; 1 = needs gestural/verbal prompts; 0 = needs no assistance.
Changes in developmental functioning: Table 3 indicates the pre-post results of the PEP-R for the 6 subscales and the developmental age score. Perception, Fine motor and Developmental age improved significantly. There were no decreases in developmental functioning in any subscale.

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Pre</th>
<th>Post</th>
<th>RCI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Imitation</td>
<td>14-15</td>
<td>20-22</td>
<td>1.80</td>
</tr>
<tr>
<td>Perception</td>
<td>7-8</td>
<td>16-18</td>
<td>2.09*</td>
</tr>
<tr>
<td>Fine motor</td>
<td>12-13</td>
<td>24-26</td>
<td>3.66**</td>
</tr>
<tr>
<td>Gross motor</td>
<td>23-24</td>
<td>25-27</td>
<td>0.60</td>
</tr>
<tr>
<td>Eye-hand integration</td>
<td>14-17</td>
<td>14-17</td>
<td>0.00</td>
</tr>
<tr>
<td>Cognitive performance</td>
<td>11-12</td>
<td>14-15</td>
<td>1.11</td>
</tr>
<tr>
<td>Verbal skills</td>
<td>16-17</td>
<td>16-17</td>
<td>0.00</td>
</tr>
<tr>
<td>Developmental age</td>
<td>15</td>
<td>18-21</td>
<td>2.26*</td>
</tr>
</tbody>
</table>

* Estimated developmental age in month; ** RCI computed using standard deviations and internal consistencies based on a reference group of children with ASD (N = 33; age range: 6 – 9 years) reported by Villa, Micheli, & Villa (2010) *p ≤ .05; **p ≤ .01

Social Acceptance: Caregivers stated consistently the intervention as being helpful and disburdening. L was described as more communicative in everyday life, more predictable and less aggressive. In addition, caregivers reported a better comprehension of the functional relevance of her behaviour problems, as with challenging behaviour to gain attention or with aggressive reactions in demanding situations. Likewise, the mother stated her satisfaction with the intervention. The telephone conversations were informative and helpful, as stated by the mother and by the author as well.

3.1.4 Conclusions The TEACCH-based intervention has proven to be effective in reducing problem behaviour consistent with the literature (Schopler et al., 1995). Results on the BPI revealed no statistical significance (in reference to an adult sample, as there were no children norms), but nonetheless a considerable trend of symptom reduction supported by the meaningful improvement in especially burdening behaviours (see critical incidents, 3.1.3).
The client showed a significant improvement in the autonomous handling of her schedule and choice board, although she needed minimal verbal prompts up to the end of intervention. The schedule was accepted by the client and improved her understanding of the course of each session. The choice board was used in a socially interactive manner and helped improve the client’s understanding of communicative interactions. The results in the PEP-R indicate an overall positive trend in developmental functioning, particularly with regard to the subscales which were focused on in the intervention. Furthermore, enhanced cooperation as a result of the intervention had a considerable influence on the positive PEP-R results. The disability concept, in particular functional aspects of behaviour problems, was mediated to caregivers and parents, as shown in informal interviews.

**Limitations:** Baseline measurements of social-communicative abilities consisted only of data of the four sub-sessions of session 1. Furthermore, results of single-case studies in general only allow tentative conclusions to be drawn. Implementation of key aspects of the intervention (e.g., the choice board) in everyday life was only partially realised. A supportive pedagogical framework and respective organizational aspects could contribute towards a better everyday life implementation. However, given the acceptance of the program by both parents and professional caregivers a generalisation of intervention effects to everyday life might be obtained in future.

The study showed the successful implementation of chosen elements of the TEACCH-Program within remedial residential care in Germany under reasonable economical effort. Considering the relevance of evidence-based treatments in psychosocial health care in Germany and the given deficit of controlled studies in the German speaking world, more research is necessary.

### 3.2. Evaluation of a TEACCH-based intervention for adults with autism spectrum disorders in a residential and vocational setting

#### 3.2.1 Theoretical background and aims of the study

Autism Spectrum Disorders persist through the life-span and carry the risk of developing additional emotional and behavioural disorders (Hutton, Goode, Murphy, Le Couteur, & Rutter, 2008). There are a number of studies which show the effectiveness of TEACCH, particularly for children with ASD (Mesibov & Shea, 2009). However, only a few studies exist which focus on the possible positive influence of TEACCH on adults with ASD in residential and vocational settings (Persson, 2000; Van Bourgondien, Reichle, & Schopler, 2003; Siaperas & Beadle-Brown, 2006). The present study is the first that evaluated possible influences of TEACCH on adults with ASD in a day care setting in Germany.

**Aims:** With regard to the goals of the TEACCH program (Mesibov et al., 2006) and the aforementioned studies the following hypotheses were formulated: (1) There would be a substantial reduction in behaviour problems (e.g., disruptive and/or self-absorbed behaviour) as a result of the
TEACCH intervention; (2) participants would show more positive social-communicative behaviour and less negative social-communicative behaviour after the implementation of TEACCH; and (3) the social validity (Foster & Mash, 1999) of TEACCH is rated highly by the caregivers.

3.2.2 Method

3.2.2.1 PARTICIPANTS The sample consisted of two illiterate adults (T, male, aged 34 and M, female, aged 23) with diagnosed autism and severe mental retardation living in a residential home and one male literate adult (B, male, aged 30) with diagnosed PDD-NOS and moderate mental retardation living with his parents. All three participants attended a day care centre for adults with disabilities half-day in which parts of TEACCH were implemented 4 years ago. Three staff members, trained in TEACCH, who knew the participants for 5 years on average, rated them with following instruments.

3.2.2.2. MEASURES (a) Developmental Behaviour Checklist for Adults (DBC-A): The German version of the DBC-A by Einfeld, Tonge and Steinhausen (2007) (original by Einfeld & Tonge, 2002) was used to attain measures of the participants’ problem behaviour. Respondents are required to rate the presence or absence of specific behaviours on a 3-point scale (0 = not true, 1 = somewhat or sometimes true, 2 = very true or often true). The scale consists of six subscales (disruptive, self-absorbed, communication disturbance, anxiety/antisocial, social relating, depressive) whereof disruptive (e.g., “kicks, hits”, “noisy”, “impatient”; internal consistency (Cronbach’s) = .88) and self-absorbed (e.g., “repetitive actions”, “no sense of danger”, “hits self”; internal consistency = .89) are reported in this study as well as the Total Problem Behaviour score (internal consistency = .95).

(b) Matson Evaluation of Social Skills for Individuals with Severe Retardation (MESSIER): The MESSIER by Matson (1995) was used in a German translation by Martin, Jung, Micheel and Probst (2008) to assess the participants’ social skills and social behaviour. Respondents rated on a 4-point Likert scale whether each of the 85 statement is true of the participant (0 = never, 1 = rarely, 2 = sometimes, 3 = almost). The items are grouped into six clinically derived subscales: positive verbal (e.g., “communicates most needs verbally”), positive nonverbal (e.g., “smiles in response to positive statements”), positive general (e.g., “shows interest in activities of other people”), negative verbal (e.g., “makes loud inappropriate noises”), negative nonverbal (e.g., “exhibits peculiar or odd mannerisms in public”), and negative general (e.g., “often does not attend to people or the environment”). An overall score, the MESSIER Adaptive Scale Score (MASS; internal consistency (Cronbach’s) = .94; Matson, Dixon, Matson, & Logan, 2005) is calculable. The scale is considered to be reliable (Matson, Leblanc & Weinheimer, 1999) and valid (Matson, Carlisle, & Bamburg, 1998).

(c) Behavior Problems Inventory (BPI): For description of the BPI by Rohjan et al. (2001) see section 3.2.1.3 in this paper.
(d) TEACCH evaluation caregiver interview: A semi-structured interview was conducted with each staff member (duration: about 20 min.). Questions included (a) general advantages and disadvantages of TEACCH, (b) the pro and cons of TEACCH regarding each participant, (c) possible influences on the participant-caretaker-interaction, and (d) possible relief or strain caused by the implementation of TEACCH for the staff members.

3.2.2.3 Intervention Each of the three participants used individualized daily schedules and work systems following the principles of Structured Teaching (Schopler et al., 1995).

(1) T used a pictorial daily schedule, which always showed a picture of T and the responsible caregiver on the far left. The picture cards were applied in chronological order from left to right. Each card represented an activity and told T what would be next and where it would take place (e.g., the card with a cup told T that it was time for breakfast and he had to go to breakfast room; the yellow card meant “Have a break, go to the break room!”). After an activity was finished, T put the card into the matching pocket on the far right and took another card from the left to start the corresponding activity. A typical daily-schedule, for example, consisted of a yellow break card followed by the work card and then a yellow break card, followed by the cup card, again yellow break card, followed by a scenery card (means going for a walk), plate and cutlery card (= lunchtime), and finally a yellow break card.

His work system, installed on an individualised work place, followed also a left-to-right routine whereas the working materials were organized in a shelf to the left (in a top-down-order). After completing one task, T put the object into the finished box to his right. Four cards with numbers from 1 to 4 (on the desk) assured that T knew which task to do next (the corresponding cards were installed on the according rack bay on the shelf to his left). T took one number card, placed it next to the corresponding one and took the working material to his place. Typical tasks for T were puzzles or file folder tasks. After all four tasks were completed, T took the last card which told him to go back to his pictorial daily schedule and take the next activity card.

(2) M used a daily schedule consisting of physical objects. These objects where also applied on a chronological order from left to right. Each object stood for a different activity (e.g., the red place mate told M to go to her work place and start working). After completion of an activity, M returned to her schedule and put the object in the finish box (on top of the schedule). At her workplace M followed a left-to-right routine, where the to-do tasks were provided on the left and were put into the finished box on the right after completion. M typically completed puzzles or shoebox tasks (Larsen, 2010).

(3) B used a pictorial daily schedule as well as a written work system. His schedule was a folder in which the activities (each presented as a picture
card with the appropriate word) were chronological organized from top left to bottom right. After completing an activity he reversed the corresponding card so it showed a blank card. B’s work system was similarly designed: Ten work steps, each presented as a sentence on a card, where chronologically organized in a folder. After completing each task B turned the card around and went on with the next work step. Guided by this system B built complete pocket books.

3.2.2.4 Procedure Each participant was rated by two staff members with each of the aforementioned questionnaires two times: The first referred to the “point in time of investigation (t2), and the second to “before the implementation of TEACCH” (t1) and was thus a retrospective rating.

3.2.2.5 Data Analysis Although each participant was evaluated by two raters, the data of only one could be analysed for B and T. The qualitative analysis was obtained by methods analogue to the “Qualitative Content Analysis” by Mayring (2000). Because of the high similarity of the statements, no anchors are reported. A mean Reliable Change Index (RCI; Jacobson & Truax, 1991) for all three participants as well as an individual RCI was calculated to reveal possible pre-post gains.

3.2.3 Results Results for the quantitative measures are summarized in Table 4. A dependent t-test for paired samples revealed the following: The following results in the DBC-A could be shown: (a) a significant reduction in disruptive behaviour; (b) self-absorbed behaviour decreased significantly; c) the Total Problem Behaviour score dropped from t1 to t2 significantly; d) the MESSIER Adaptive Scale Score improved from t1 to t2 significantly; and e) no significant changes could be shown in the BPI Full Scale Score and for the subscales of the BPI though the results were all in the predicted way (e.g., aggressive/destructive behaviour decreased. The RCI revealed significant changes for the mean RCI (M-RCI) as well as for the individual RCI of all 3 participants for the DBC-A Disruptive Scale and the DBC-A Total Problem Behaviour. Further, the M-RCI showed significant reduction of the BPI-Stereotyped Behaviour Score, whereby the stereotyped behaviour of 2 participants decreased significantly from t1 to t2. The RCI for the BPI Full Scale Score revealed a significant reduction of problematic behaviour over time for 1 participant.
Interview content analysis: All three staff members reported as general advantages (a) the principles of Structured Teaching, for example, implemented by using individualized daily schedules, leading to reduced uncertainty by the participants and less misunderstandings, (b) enhanced communication between caregivers and participants, (c) reduction of the dependency of one particular caregiver with an increase in participant’s independence and autonomy at the same time. As a possible disadvantage all three caregivers named the reduction in flexibility through Structured Teaching. But they also noted that it was their responsibility to keep this in mind. At first, the implementation of TEACCH meant more effort for the caregivers but then was seen as a relief. Achieved individual milestones through the implementation of TEACCH that were reported concordantly

Table 4 - Results of quantitative measurements

<table>
<thead>
<tr>
<th>Scale</th>
<th>M (SD) t1</th>
<th>M (SD) t2</th>
<th>T</th>
<th>M-RCI</th>
<th>n RCI (+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>DBC-A Disruptive</td>
<td>20.67 (4.51)</td>
<td>12.83 (4.01)</td>
<td>17.76**</td>
<td>2.43a</td>
<td>3</td>
</tr>
<tr>
<td>DBC-A Self-Absorbed</td>
<td>27.33 (14.15)</td>
<td>20.50 (14.29)</td>
<td>15.50**</td>
<td>1.12a</td>
<td>0</td>
</tr>
<tr>
<td>DBC-A Total Problem Behaviour</td>
<td>75.50 (21.64)</td>
<td>55.17 (22.67)</td>
<td>16.92**</td>
<td>2.55a</td>
<td>3</td>
</tr>
<tr>
<td>MASS</td>
<td>98.39 (64.14)</td>
<td>116.78 (66.80)</td>
<td>-11.98**</td>
<td>1.32a</td>
<td>0</td>
</tr>
<tr>
<td>BPI-Self-Injurious Behaviour</td>
<td>11.33 (9.87)</td>
<td>8.16 (7.08)</td>
<td>1.82</td>
<td>0.75c</td>
<td>0</td>
</tr>
<tr>
<td>BPI Stereotyped Behaviour</td>
<td>35.67 (20.26)</td>
<td>30.17 (17.55)</td>
<td>2.69</td>
<td>2.44c</td>
<td>2</td>
</tr>
<tr>
<td>BPI Aggressive/Destructive Behaviour</td>
<td>12.83 (7.85)</td>
<td>4.16 (3.25)</td>
<td>2.50</td>
<td>0.88c</td>
<td>0</td>
</tr>
<tr>
<td>BPI Full Scale</td>
<td>59.83 (37.90)</td>
<td>42.50</td>
<td>2.37</td>
<td>1.78c</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: DBC-A= Developmental Behaviour Checklist Adults; MASS= MESSIER Adaptive Scale Score; BPI = Behaviour Problem Inventory; M-RCI = Mean Reliable Change Index; n RCI (+) = individual significant RCIs; t1 = before the implementation of TEACCH; t2 = point in time of investigation

*a calculation of individual RCI-Scores based on R (internal consistency) and SD reported by Einfeld and Tonge (2009)

*b calculation of individual RCI-Scores based on R (internal consistency) reported by Matson et al. (1999) and SD by Matson and Boisjoli (2008)

*c calculation of individual RCI-Scores based on R (internal consistency) and SD reported by Gonzales et al. (2009).
where (a) T behaves significantly less aggressively, (b) M goes now to the toilet by herself, and (c) B engages now in meaningful action instead of sitting around and starring at the wall.

3.2.4 Conclusions The applied qualitative and quantitative methods show coherent results consistent with the tested hypotheses. (1) There was a significant reduction in disruptive and self-absorbed behaviour as well as general behaviour problems following the intervention. (2) Participants showed more positive social-communicative behaviour and less negative behaviour after the implementation. (3) All three caregivers reported a high acceptance of the intervention’s goals, methods and effects. Thus, the social validity is high.

The major limitations of the study are the retrospective design as the ratings could be biased in a number of ways (Gilovich, Griffin, & Kahnemann, 2002). Additionally, the sample was not attained randomly and was very limited.

Despite the methodological limitations, the results of this study are in accordance with other TEACCH evaluation studies and support the assumption that TEACCH is an effective evidence-based intervention method to help people with ASD take part in daily life.

4. Overall conclusions

In the present synthesis, two TEACCH-based tertiary prevention studies with individuals with autism were presented. Common aims of tertiary intervention included: (a) reducing behavioral symptoms, enhancing social-communicative abilities and thus strengthening autonomy and social participation in persons with autistic disorders, and (b) enhancing behavioral and emotional coping abilities of caretakers in family, classroom and residential-vocational institutions.

Theoretical framework: Research and clinical practice were guided by a theoretical framework comprising the “expanded ABCX-stress-coping model” (adapted from Pakenham et al., 2005) and the Structured Teaching concept, developed by the TEACCH group (Schopler, 1997) and based on the integrated use of behaviour and cognitive theory (Schopler, 2005). The various settings included a residential group home for children and a day care centre for adults. The theoretical framework selected proved to be useful for deriving aims and methods for performing interventions in both settings, and for evaluating the outcomes.

Methodology: The evaluation methodology followed a multimethod strategy. The broad spectrum of methods used for evaluation included behavioral observation, standardized tests, questionnaires, inventories and interviews. This methodological approach turned out to be useful for estab-
lishing a “holistic” perspective (Schopler, 2005) of understanding the needs of individuals with a long-life disability rather than focussing on singular domains and deficits.

Results: Overall, the results of both studies provide evidence for positive outcomes of TEACCH-based interventions across multiple individuals, ages, settings and measures. These findings are in congruence with a number of international evaluative studies (Probst & Leppert, 2008; Mesibov & Shea, 2009; Panerai et al., 2009). Further, the caregivers’ satisfaction with the programs was generally high, and the demands on caregivers appeared to be adequate and realistic. This positive finding is also consistent with the literature (Mesibov & Shea, 2009).

Limitations: There are however limitations to the experimental validity of the presented studies. Threats to the internal validity include small sample size and lack of control groups in the second study, and lack of extensive baseline assessment in the first study. In addition, experimental control in the second study is reduced due to the absence of a real-time pre assessment measurement of outcome variables. Threats to the external validity include the small and selective sample in the second study. Further, the effects of the single-subject study can be generalized only with caution.

Final conclusions: Under consideration of the restricted internal and external validity, which are not unusual for first-step evaluations of comprehensive programs in new sociocultural contexts, the following conclusions can be drawn:

(1) The present synthesis supports the assumption that TEACCH-based interventions lead to clinically and educationally relevant effects with regard to child outcomes in group home settings, and adult outcomes in residential and day care settings.

(2) Both studies showed the feasibility of the TEACCH-approach in various settings. Overall, the outcomes support the assumption that TEACCH-based interventions are also practicable in German-speaking countries. They are compatible with local approaches of tertiary prevention that emphasize holistic methods enhancing the individual’s autonomy and social participation. Further, highly technical terminology opposed by the majority of health professionals is avoided, and TEACCH-based interventions allow low-threshold access for caregivers of children with autism, and thus are in accord with common personal and social resources of families, classrooms, and related social institutions. Thus, TEACCH-based interventions, as examined in the current studies, largely proved to be compatible with strategies of local health care systems in Germany.

Future research: Further research should include (a) controlled group studies with individuals with autism, and caretakers as mediators, (b) stricter controlled single subject studies using multiple baseline designs,
and (c) studies systematically examining the impact of symptomatology, developmental functioning, and personality on intervention outcomes. Research strategies of this kind will hopefully increase the implementation of empirically supported interventions for the treatment of children and adults with autism.

References


Tertiary-preventive interventions for Autism Spectrum Disorders (ASD) in children and adults


The Five Minute Speech Sample as a measure of parental Expressed Emotion in the field of disability

Loredana Laghezza, Claudia Mazzeschi, Daniela Di Riso, Daphne Chessa & Livia Buratta

Abstract

The purpose of this paper is to provide a review of research literature that has assessed Expressed Emotion (EE) with the Five Minute Speech Sample (FMSS) in parents of children with intellectual disabilities (ID). Very little attention has been paid to the parenting relationship in families in which a member has cognitive disabilities. The research that has been carried out has investigated interactive features by means of comparing groups of children with typical development and sample groups of at-risk and disturbed children. Specifically, the literature on Expressed Emotion in parents of children with intellectual disabilities is sparse. A study of PsycINFO found eleven articles about EE in families of adults or children with cognitive disabilities. In these studies, EE was measured by using the CFI or the FMSS.

Keywords: Expressed Emotion, FMSS, Intellectual Disabilities
1. Introduction

Over the last two decades the literature on parenting has considered EE as a new dimension for studying the child-parent relationship linked to the emotions. Expressed Emotion (EE), is a qualitative measure of the ‘amount’ of emotion displayed, typically in the family setting, usually by a family member or caregiver. EE measures hostility, warmth, and positive remarks. It was developed as a measure to assess expressed emotion (EE) in relatives of adult patients with mental disorders (including schizophrenia, bipolar disorder, depression, and eating disorders) and to predict relapse in these patients (Vaughn & Leff, 1976; Eisenberg, Thompson, Fabes, Shepard, Cumberland, Losoya et al., 2001; Hooley & Parker, 2006).

Brown and his colleagues in several studies (Brown, Birley, & Wing, 1972; Brown, Monck, Carstaire & Wing, 1962; Brown & Rutter, 1966) found that when a patient with schizophrenia – and for this reason hospitalized - had a parent with high EE and this parent was very close to him, the patient had more risk of a relapse after having been discharged from the hospital. Other research (Vaughn & Left, 1976; Miklowitz, Strachan, Goldstein, Doane, Snyder, Hogarty et al., 1986; Goldstein, Talovic, Nuechterlein, Fogelson, Subotnik, & Asamow, 1992) confirmed that patient who lives or returns to a family context with high EE, had more probability to have a relapse than the patient who returned from his hospitalization to a family with low EE. So it seems that the families that express the emotion in an inadequate and excessive way toward the relative produced stress for him and this did not favor his readjustment and the recovery of his abilities.

The first method to measure EE is the Camberwell Family Interview (CFI; Leff & Vaughn, 1985). The most predictive sub-scales of the CFI are relative to criticism, hostility and emotional over-involvement. Criticism is defined as unfavorable comments about a family member; hostility is defined as generalization of criticism or hostility, and emotional over-involvement consists in over-protective behavior, devoted behavior and exaggerated emotional response. All research conducted from the years 1960 to 1990 has used the CFI as Hastings and Lloyd (2007) showed in their literature review. They have demonstrated that CFI has been the principal method for EE in different cultural contexts. In 1986 Magana and colleagues introduced a new method for EE: the Five-Minute Speech Sample (FMSS; Magana, Goldstein, Karno, & Miklowitz, 1986). The FMSS is a brief method, based on the CFI, designed to assess the respondent’s expressed emotional (EE) status toward a family member.
2. The Five Minute Speech Sample

The FMSS-EE rating is derived from statements made by a patient’s relative during a 5-minute monologue. Parents or relatives are asked to describe “who is” their child and “how is” their relationship with the child. They are required to talk about their feelings and thoughts in their own words and describe the emotional climate between them and the child, without interruption. The FMSS is audio-recorded and coded, regarding both content and emotional tone, into a grid which includes the emotional involvement of the parent as derived from emotions, feelings and attitudes expressed in the monologue (Magana et al., 1986). The final classification can be High EE, high-level of emotional expression, characterized by an excessive presence or intensity of the emotions, often beyond the control of the subject and scarcely modulated; or, low EE, low level of expressed emotion, characterized by a well modulated and balanced level of communicated emotion. The FMSS measure comprises two distinct components: criticism (CRIT) and emotional over-involvement (EOI) that are subsumed under the more general labels of High EE and Low EE. There are also seven sub-profiles of EE (High CRIT, High EOI, High CRIT/EOI, Borderline CRIT, Borderline EOI, B CRIT/EOI, Low) that are the result of a combination of different scores in the coding sheet. These different profiles assessed these two components the criticism and level of emotional involvement expressed. High criticism is scored when a) the first statement is negative, b) the parents describe a negative relationship with the child, or c) the parent criticizes the child. Emotional over-involvement is scored when a) parents express clear demonstrations and exhibitions of emotions, b) statements of attitude, c) behaviours of self-sacrifice or excessive protection, d) excess of details in their description of the family and e) attribution of more than five positive adjectives to the family member.

There is also promising concurrent validity data with the CFI (Magana et al., 1986; Moore & Kuipers, 1999; Calam & Peters, 2006). Several research now used the FMSS as EE measure because it is reliable, quicker to administer and takes much less time to code.

3. EE in developmental age: psychopathology and disabilities.

The research on parenting included the use of different measures: self-report measures (questionnaires or scales), interviews, observations of interaction, and a combination of these measures. Each instrument has its limits and potentialities. In the last decades EE has been considered as a new and effective measure of parenting and family functioning. There is strong evidence of positive associations between parental attitudes and behaviours and child development in normal and pathological children and in

In parenting literature, Expressed Emotion is a measure of family members’ emotional attitudes toward a child and the FMSS is a narrative instrument to assess this.

However, recent interest in EE has explored its utility as a measure of the emotional relationship between parent and child. Specifically, the construct of EE has been related to a wide range of childhood problems including asthma (Wamboldt, O’Connor, Wamboldt, Gavin, & Klinnert, 2000) depression (Asarnow, Tompson, Woo, & Cantwell, 2001), eating disorders (van Furth, van Strien, van Son, & van Engeland, 1993), conduct disorders (Eisenberg et al., 2001) and cognitive disabilities (Beck et al., 2004).

If, on the one hand, these studies observed positive associations between high parental EE and child psychopathology, on the other, these results open new research perspectives concerning the role of EE parental functioning in respect to the: 1) presence of risk conditions in the child; 2) the relationship and possible interaction with other dimensions of parental functioning. Research has demonstrated a strong reciprocal influence between all these aspects: a bidirectional relationship between parent and child such that the well-being of one is influenced by the other (Falloon, Boyd, McGill, Williamson, Razam, Moss et al., 1982).

There are few studies of expressed emotion in families of children with intellectual disability. In the interests of future research and the considerable clinical implications of this question, we decided to focus the present review on an analysis of EE in parents of children with cognitive disabilities.

4. Expressed Emotion and cognitive disabilities

The present review is specifically aimed on the research regarding EE in samples of parents of children with ID, intellectual (or cognitive) disabilities. Intellectual disability (e.g.: mental retardation) is described by the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) as the presence of a sub-average general intellectual functioning associated with or resulting in impairments in adaptive behavior in several areas: communication, personal care, family life, interpersonal and social relationships, use of resources in community, self-determination, scholastic functioning, work, leisure time, health and safety. The onset of this disability occurs before the age of 18. The subjects with ID has strong vulnerability to psychiatric disorders, they have a 5 to 7 times greater likelihood of developing these disorders than in the
People with moderate or low disorder manifest behavior problems, emotional problems such as anxiety or depression, obsessive-compulsive symptoms and attention deficit. Subjects with severe level of intellectual disabilities have more autistic disorders, aggressive behavior, schizophrenic symptoms. The label ‘intellectual disabilities’ can be considered as a broad and non homogenous category, that include different clinical conditions (from mental delay to autism) and with different degrees of severity.

Very little attention has been paid to the parenting relationship in families in which a member has cognitive disabilities. The research that has been carried out has investigated interactive features by means of comparing groups of children with typical development and samples of at-risk and disturbed children (Friedrich & Friedrich, 1981; Roach, Orsmond, & Barratt, 1999; Lardieri, Blacher, & Swanson, 2000).

Specifically, the literature on EE in parents of children with intellectual disabilities is sparse. A study of PsycINFO found eleven articles about EE in families of adults or children with cognitive disabilities. In these studies, EE was measured by using the CFI (Leff & Vaughan, 1985) or the FMSS (Magana et al., 1986). The purpose of this paper is to provide a review of research that has assessed EE with the FMSS and only to give the reference of the studies that have used CFI: Greedharry, 1987; Dossetor, Nicol, Stretch, & Rajkhowa, 1994; Clerici, Bertrando, Beltz, Fornara, Iraci, Steiner et al., 1998; Lam, Giles, & Lavander, 2003).

5. FMSS and cognitive disabilities

The first study of the EE construct in families of children with cognitive disabilities was that of Datta, Russell and Gopalkrishna (2002). They conducted a research on the role of caregivers in India. In this study, the first data appeared about the EE of 31 parents of 3-16 year old children with intellectual disability. Participants were recruited from a care centre that provides service for family with children that have mild or profound level of intellectual disability. The caregivers were enrolled either in a day care therapy program and also in a residential therapy program. The family attended therapy for an average of three months. In the study were included the caregivers of children between 3 and 16 years of age with DSM-IV diagnosis of intellectual disability (American Psychiatric Association, 2000); the diagnosis was confirmed with the Binet-Kamat Scale of Intelligence (Indian adaption of Intelligence Scale Stanford Binet-Kamat, 1967) and with Gesell’s Development Scale of Intelligence (Gesell, 1940), a measure of developmental abilities of children in motor, behavioral, linguistic and social areas. The exclusion criterion was a presence of any psychiatric morbidity in...
the caregiver, evaluation with a semi-structured, clinical interview based on DMS-IV diagnostic criteria. The measures had the aim assessing the burden among the caregiver in the day care of children with ID. The caregivers that give their informed consent, met the researchers in two different sections. Each assessment section required approximately 2 hours. In the first session the researcher conducted the clinical interview in order to assess the health mental state of parents and also administered them the FMSS. In the second session the parents completed the Vineland Social Maturity Scale (Doll, 1935) and the Family Burden Interview Schedule (Pai & Kapur, 1981), a standardized instrument developed for the Indian population to measure the family’s perceived burden in six areas: financial, effects of family routine, effects on family leisure, on family interactions, on physical and mental health of other family members. The sample group was composed of 19 mothers, 11 fathers and one grandmother. The children’s group with ID was composed of 22 males and 9 females. Datta and colleagues (2002) found high CRIT in 39% and high EOI in 61% of the sample. The presence of high EE predicted a high level of burden among the caregivers. This study has several methodological limits: it is not clear how EE is measured, the labels of criticism and EOI are used but it is not specified how they are coded, percentages of total EE are not given, and it is not clear how the parent’s role was assessed. The validity and reliability of the research are very weak and the conclusion of this research is therefore very uncertain.

Beck et al. (2004) in their study aimed to identify the dimensions of parenting that, together with child variables (adaptive or problematic behaviour), may affect the EE in mothers. The authors also explore EE towards two children (one with ID and another without ID) in the same family to understand if EE is determined by child factors or if it is reflected in general mothering characteristics. The FMSS in this research was administered by telephone to the mothers of children with intellectual disabilities and with siblings without any clinical condition close in age to the disabled child. The mothers provided a FMSS for their children with ID and another for a sibling close in age to the child with ID. The sample included 33 mothers (mean age = 41.93 years, SD = 6.14) of children with cognitive disabilities including 18 with Down’s Syndrome. The mean age of the children was 9.02 years (SD = 3.54, range 4-14 years) and there were 15 males and 18 females. The maternal measures were: the Block Child Rearing Practices Report (Rickel & Biassatitill, 1982) focused on parental beliefs, the Sense of Competence Scale (PSOC; Johnston & Mash, 1989) to evaluate the parenting satisfaction and efficacy, and the FMSS. The children measures were the Strengths e Difficulties Questionnaire (Goodman, 1997), to evaluate the behavioral disorder and the Vineland Adaptive Behavior Scale (Sparrow, Balla, & Cicchetti, 1984) to assess the adaptive behavior in the child. The results of the study reported that high EE toward the child with cognitive disabilities was found for 60% of mothers. The children who had moth-
ers with higher EE also had greater behavioural problems, more problems of conduct and more hyperactive behaviours. The mothers with higher EE were also less satisfied with their parenting abilities than mothers with low EE. Differences were found in EE towards the two siblings regarding criticism, initial statement, positive comments, self-sacrificing behaviour and EOI. Overall, the mothers expressed higher EE toward a child with ID. The maternal EE towards a child with ID was more negative than EE towards their children without ID. This research had a strong methodological structure. The researchers showed the validity of EE derived from FMSS administered by telephone which was compared with a small group of FMSS proposed face-to-face. They found a complete correspondence in the final coding and the study also had a good level of inter-rater reliability ($k = 0.80$), test-retest reliability ($k = 0.75$), and a strong consistency of code re-code reliability ($k = 0.90$).

Later, Hastings, Daley, Burns and Beck (2006) conducted a longitudinal study in which they examined EE in 75 mothers of children with intellectual disabilities. The FMSS was administered to 56 of these mothers two years later. The cross-sectional longitudinal study has the aim to assess the maternal distress, mental health, expressed emotion and the child’s internalizing and externalizing behavior problems. The study included at the same time 1, 75 mothers and their children with ID (50 males, 25 females) had a mean age of 9.75 years ($DS = 4.04$). Twenty-four children had a diagnosis of autism and 26, Down Syndrome. The remaining children had no diagnosis in addition to their intellectual disabilities.

Based on the Vineland Adaptive Behavior Scale (Sparrow et al., 1984) 31% of the children had severe to profound developmental delay and the remainder had mild or moderate developmental delay. Forty percent of mothers did not work outside of the home, 35% were in full-time work and the remainder, in part-time. The majority of mothers were living with a spouse or other partners (83%); 17% of mothers were single parents.

At time 2, after two years, the mothers who continued to participate in the research project were 56. The children’s group was composed of 35 males and 21 females, 20 children with autism and 20 with Down Syndrome; the mean age at time 2 was 11.72 years ($DS = 3.92$). The comparison between two groups of mothers and their children who participated at both time points did not show differences, suggesting that the sample at time 2 was a reasonable representative of the initial study sample. The measures for children were reported by the Vineland Survey form, and the assessment of behavioral problems through the Strengths e Difficulties Questionnaire (Goodman, 1997). The maternal measures were the la Hospital Anxiety e Depression Scale (Zigmond & Snaith, 1983) to assess their mental health, the Parent Stress Index-SF (Abidin, 1990) to assess the parenting stress and the FMSS to measure the expressed emotion of mother toward the child. They reported that 52% of mothers ($n = 39$) at time 1 presented
high EE: 16 mothers reported high CRIT, 13 mothers high EOI and 10 mothers both high CRIT and EOI. After two years, 61% mothers reported the same coding of high CRIT and 70% presented the same level of high EOI. Both maternal criticism and over-involvement showed evidence of stability over two years. As in research with children with no disability, statistical coefficients suggested instability over two years (Peris & Baker, 2000). In this study the clear majority of mother expressed emotion codes that did not change from time 1 and time 2. Beck et al. (2004) confirmed the previous results when they found a positive association between high CRIT and behavioural problems in the child, and high stress level in mothers. They did not find any associations between EOI and the child’s externalizing problems. The study presented a good level of reliability; the code-recode reliability was 100% for CRIT coding and 83% for EOI coding, inter-rater agreement reliability was 83% for CRIT and 94% for EOI.

Greenberg, Seltzer, Hong and Orsmond (2006) and Orsmond, Seltzer, Greenberg and Krauss (2006), conducted a study with mothers of adolescents and adults with diagnosed autism 50% of whom also had intellectual disabilities. They used the same sample and carried out two different analyses on the data at time 1 with 202 mothers (Orsmond et al., 2006) and time 2 with 149 mothers (Greenberg et al., 2006). The results at time 1 showed that 28.7% of the sample was coded as high EE, 19.3% of mothers presented elevated CRIT and 10.9% presented high EOI; only 10.4% did not express warmth. The first study presented good inter-rater reliability ($k = .67$). Orsmond and colleagues (2006) also used the Warmth variable derived from the CFI coding system and for this variable they also showed a good level of inter-rater reliability ($r = .79$). The authors found a positive association between high CRIT, behavioural problems in the adolescents or adults and pessimism in the mothers. They then observed positive relationships between high EOI and greater difficulties in language, and poorer health of the adolescents (or adults). The mothers who are married showed a higher level of warmth and lower level of pessimism toward their children. These results were confirmed in the second analysis (Greenberg et al., 2006) with 149 mothers. After 24 months, Greenberg and colleagues (2006) found that 72% presented the same coding categories as time 1 (Orsmond et al., 2006) according also to Hastings’ findings. These results were in agreement with the percentages presented in Hastign et al. (2006) research. Greenberg and colleagues also demonstrated that high EE, and high CRIT predicted externalizing behavioural problems and asocial behaviour, but no positive association was found for EOI and behavioural difficulties in general. The children with internalizing problems had mothers with lower levels of EE over time. The results also showed that EE and high CRIT predicted symptoms of autism to a limited extent over time, and again no associations were found with EOI. The results also showed a gender effect: the mothers of females with autism presented higher levels of EE and higher
criticism while the mothers of subjects with diagnosed autism and also intellectual disabilities presented a lower level of EOI.

From a review of these studies that assessed the EE construct with FMSS which were conducted with caregivers of children or adults with intellectual disabilities, it was found that 30%-60% of parents presented high EE, 20%-40% showed high criticism and 10%-60% high EOI. The results demonstrate a strong association between high EE and behavioural problems in the individuals with intellectual disabilities and high levels of parental stress. There also appeared to be no consistent relationship with EOI.

6. Some considerations

Despite the weak methodological structure of these studies, if we assume that the EE construct has been measured in a reliable and valid way, several considerations about the EE’s role in the families whose members have cognitive disabilities can be made. We will analyze some implications:

a) More percentages of high EE in parents of ID children.
   Mothers of children with ID showed high EE more frequently than mothers of children without ID. High EE in both the form of high criticism or high EOI is present in families of children or adults with ID. The high level of EE is significantly present in a minority, and potentially in a majority, of families of children or adults with ID. These results have very important implications in clinical practice with caregivers of ID children. These parents need to be supported in the daily care of their children.

b) EE, disabilities, behavioural difficulties, parental stress, and social support
   The analysis shows the influence of maternal factors on EE. From a review of the literature it emerges that both maternal and child factors may have a role in determining different levels of maternal EE. Researches haven’t the aim to propose a causal model of relation between DI and family EE but they can demonstrate the complex interaction between several family factors that can produce an high EE profile associated with psychopathology in subjects with ID. Regarding maternal factors, Beck (2004) in his study, for example, observed significant associations between high maternal EE, level of parental satisfaction/stress and also the level of severity of the child’s behavioural difficulties. These findings are confirmed in other studies (Stores et al., 1998) found that mothers of Down’s Syndrome children suffered greater stress than mothers in the general population.

   In general, the research on the families of ID children has demonstrated significant associations between frequency of difficulties in the child, severity of impairment, parental stress, marital satisfaction, maternal depression,
anxiety and social support (Wikler, Wasow, & Hatfield, 1981; Quine & Pahl, 1985; Quine & Pahl, 1991; Sloper et al., 1991; Beresford, 1994; Stores et al., 1998; Gowen, Johnson-Martin, Goldman, Appelbaum, 1989; Smith, 2001; Hastings, 2003; Beck et al., 2004; Orsmond et al., 2006). In fact, many families of ID children showed a good capacity to satisfy their child’s needs and manifested good adjustment to their child’s requests (Glidden & Pursley, 1989; Glidden & Johnson, 1999; Flaherty & Glidden, 2000; Carr, 2005). Many parents were able to recognize the positive contribution of their child to them and to family life (Friedrich & Friedrich, 1981; Beckman, 1991; Dumas, Wolf, Fisman, & Culligan, 1991; Dyson, 1991; Baker et al., 2002; Emerson, 2003). From a review of the literature we have observed a strong association between a child’s behavioural difficulties and parental well-being, although from these results it is not possible to outline a causal relationship between the two variables. It emerges from studies that the behavioural problems of the child, and not other characteristics (for example limited capacity in coping or carrying out daily activities), are linked to and affect parental difficulties (Quine & Pahl, 1985; Konstantareas & Homatidis, 1989; Quine & Pahl, 1991; Sloper et al., 1991; Orr et al., 1993; Blacher et al., 1997; Hodapp, Dykens, & Masino, 1997; Baker et al., 2002; Beck et al., 2004).

c) Association between high EE and the child’s behavioural problems

Regarding the question of whether EE can be considered a risk factor for a person with ID, the results of studies suggest that parental EE may have predictive validity regarding a child’s behaviour (Greenberg et al., 2006). For example, elevated levels of hyperactivity or behavioural problems increase levels of maternal EE (Baker et al., 2002; Daley, Sonuga-Barke, & Thompson, 2003). An analysis of the literature does not allow identification of the specific processes responsible for the development and maintenance of behavioural problems and their association with higher EE.

A possible explanation may be that EE affects the parenting behaviour that has consequences on the child’s development. It has been clearly demonstrated in development psychology that parenting and caring practices influence the child’s growth (O’Connor, 2002). A difficult child’s development may be predicted by a negative parent-child interaction (Baumrind, 1993; Baldry & Farrington 2000; Jackson & Warren, 2000; Mesman & Koot, 2000). It seems clear the association between behavioural difficulties of a child with cognitive disability and the mother’s EE. The parent EE can explain some processes responsible for the development and maintenance of behavioural problems in the child. The question is important in understanding the role of parental behaviour and promoting the resolution of behavioural problems in people with ID (Hastings & Brown, 2000).

d) Is it possible to modify EE?

This question is linked to the possibility of modifying EE and at same time
reducing the risk in subjects (both children and adults) with intellectual disabilities, of manifesting behavioural problems. Some studies have showed a strong unidirectional association between high EE and development of behavioural problems; it probably reflects that EE is a parents’ trait or personality variable. Research data is unable to show whether EE is a stable characteristic of parents or a trait variable. If we assume that EE is stable, we consider that it is always present. In fact, it seems that other parental variables may be associated with EE, for example, parental stress or social support. The EE may be affected by other parental experiences; EE should therefore be considered a specific state and not a trait variable. At this point, it is important in future research to try to understand which child variables and which aspects of the social environment maintain or produce parental EE.

EE probably presents some state-like and some trait-like proprieties (Hooley, 1998). It is a measure of the parenting that provides information about the affective relationship between parent and ID child. EE is considered a result of an interaction between relatives and the person and it is possible to understand EE only within this interactive network. If we consider EE as a result of interaction, we also can assume that it is possible to modify EE with specific interventions (Falloon et al., 1982).

7. Conclusion

From a review of the literature, it is evident that very little research has been focused on EE in families of persons with ID. From a methodological point of view, few studies present good psychometric proprieties, for example, there are no studies of inter-rater, test-retest and code-recode reliabilities. Another methodological limit is the number of subjects in the samples, and the great variability in demographic and psychological characteristics. The number of subjects in samples is low (from 40 to 202 subjects) and the groups are not balanced for sex, age and clinical diagnosis. The age of participants is strongly differentiated, ranging from infancy (4 years) to adulthood (age not specified). It is therefore not possible to identify developmental trends, since studies with a deeper stratification of the sample are needed. In the sample, clinical diagnosis is also a variable; diagnoses of autism, Down’s Syndrome, and mental development delay are included in the field of ID (Beck et al., 2004; Hastings et al., 2006). It is therefore very difficult to compare results that reflect such different clinical situations. It is important that future studies use different samples in respect to the aetiology of cognitive disabilities: the psychological features of these subjects are different and they can be associated with different EE within families. It is not possible at the moment to generalize and extend the results emerging from these studies.

The present samples cannot be considered representative of the population of parents of ID children. These families are very motivated to partici-
participate in the research and they often have specific characteristics that distinguish them from other parents who have decided not to take part in the studies. Another limit of this research is that it considers only the mothers. Other important figures such as the father, siblings, grandparents or other people involved in the care of these subjects have not been included. The aspect of multiple informants is lacking in these studies, as is the assessment of general level of family well-being. It will be important to realize longitudinal research that allows us to understand the time characteristic of EE: if it a stable trait or not. These longitudinal studies will also consent to study the relationship between parent EE and child characteristics as behavioural problems that from research results seems have a positive association with high parent EE.

From a theoretical point of view, the role of parental EE in ID is not clear. Previous research has shown that expressed emotion (EE) in relatives of adult patients with mental disorders (including schizophrenia, bipolar disorder, depression, and eating disorders) predicts relapse in these patients (Butzlaff & Hooley, 1998). This result is not proven for cognitive disabilities. Research and clinic practice is required to analyze EE in this field more systematically. From an analysis of these studies, we can assume that EE has a critical role in families with members suffering intellectual disabilities, and high EE is considered a risk factor for these subjects. Several studies have shown that higher parental EE predicts behavioural problems in the child (Greenberg et al., 2006). Therefore, if we modify parental EE the risk of these problems in a child may be reduced. Greenberg et al. (2006) considered EE both a trait and state characteristics of the parent. In fact, Beck et al. (2004) has reported that mothers manifested different EE toward ID children in respect to children without ID. Other parental variables may be associated with higher parental EE, such as parental stress or social support. In the literature, authors assume that EE is a parental characteristic that becomes critical when it is exposed to marked behaviour in a child when interacting in a regular way (Hooley, 1998). EE seems to be a parental feature that is possible to change, and this result has several implications for intervention with family members of people with intellectual disabilities. Some studies have demonstrated the efficacy of intervention approaches to modify EE in other types of families (Fallon et al., 1982). There are no studies which explore the association between EE, parental and child-parent interactions in families with members with cognitive disabilities. The presence of positive correlations with other measures may cover for the actual lack of findings in literature on the construct validity of EE in the field of ID.

In conclusion, it is very important to investigate the role of EE in families with ID children or adults. This variable may explain different aspects of the relationship between parent and children with psychological problems. In order to understand the role of EE in the family relationship of
people with ID, the research should try to reinforce methodological aspects and also give more attention to the processes and findings identified.

References


Abstract

The term Self-injurious Behavior (SIB) represents behavioral characteristics that can damage body tissue. Persons with Intellectual Disability (ID) have a greater probability of developing inadequate behavior such as SIB. Literature indicates the presence of SIB in different syndromes. In the Prader-Willi Syndrome (PWS) the most frequent physical manifestation is skin-picking, which involves the arms, legs, and hands. In the Down Syndrome (DS), eyes and ears are more greatly affected by SIB. Prevalent SIB regards head-hitting and eyes. In subjects with Autistic Disturbances (AD), effects of SIB can be found more frequently in the head, hands, and legs. The more common typologies of SIB are self-biting and self-hitting. The sample was composed of 84 persons with ID and associated syndromes (PWS, DS, AD). The SIB has been identified through administering a specific assessment instrument to caregivers. 

The collected data show that self-inflicted injuries are present in all three groups. In groups with PWS and AD most common examples regard the hands, respectively 90% and 55%; subjects with DS show SIB on the mouth (48%). SIB most frequently shown in subjects with PWS are “skin-picking” (50%), in subjects with DS grinding their teeth (32%), in those with AD the prevalent SIB is “body-hand-hitting” and “body-object hitting” (41%).

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Self-injurious behavior: A comparison between Prader-Willi syndrome, Down syndrome and Autism

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Our data show some convergences with results from literature (e.g., we confirmed that in PWS the most common manifestation of SIB is “skin-picking”), while other results are not confirmed. Differences could be explained according to more restricted or wide definitions of SIB.

Keywords: Self-Injurious Behavior, Intellectual Disability, Prader-Willi Syndrome, Down Syndrome, Autistic Disorder.
1. Introduction

The definition of Self-Injurious Behavior (SIB) is an object of debate in literature. Varying degrees of broadly-defined terms for SIB exist which determine a significant variability in data about typology and prevalence.

Many Authors have elaborated differing terms (self-harm behaviors, self-injurious behaviors, self-mutilation) for behavioral symptoms that often are similar (Palmigiano, Scannella, & Buono, 2007). Others have defined self-inflicted injury as behavior that produces immediate and cumulative physical damage to one’s own body (Tate & Baroff, 1966). The SIB is often shown in diverse clinical conditions - especially when they are characterized by severe pathologies - such as epilepsy, muscle-nerve disorders, hearing diseases, communicative disabilities, stereotypical behaviors (Emerson, Kiernan, Alborz, Reeves, Mason, Swarbrick et al., 2001).

The SIB often can block the process of one’s personal growth and the opportunity to integrate into society subjects with these disorders; besides this, it can be the reason for the failure of rehabilitation and integration efforts in community contexts (Hill & Bruininks, 1984).

Persons with Intellectual Disability (ID) are more vulnerable to psychopathologies. In such groups of persons, the comorbidity is estimated three or four times superior respect to the general population.

During these subjects’ lifespan, some can develop behavioral disturbances at different levels manifesting themselves in the form of aggressive and destructive conduct, violent fits of anger, stereotyped or self-injuring behavior (Symons & Thompson, 1997; Rojahn, Tassé, & Morin, 1998; American Psychiatric Association, 2000).

The most common forms of SIB associated with ID, as shown in literature, seem to be: self-biting, head-banging, and self-scratching. As cited above, there is little agreement about hair pulling (Arzeno Ferrao, Almeida, Bedin, Rosa, & D’Arrigo Busnello, 2006), onicofagy (Wells, Haines, Williams, & Brain, 1999), and sometimes skin-picking (Keuthen, Wilhelm, Deckersbach, Engelhard, Forker, Baer et al., 2001; Singareddy, Moin, Spurlock, Merritt-Davis, & Uhde, 2003), considered often as phenomena explained in a spectrum of obsessive-compulsive behaviors, or as deficit of impulse control.

In DSM-IV-TR (American Psychiatric Association, 2000) the term self-inflicted injury can be adopted in disturbances of stereotyped movements described as repeated motor-nerve behavior apparently intentional and a-finalistic which for themselves can be specified as self-injury behavior if such behavior can cause physical damage which requires specific treatment, or could cause physical injury if protective measures are not taken.

The 10th Revision of The Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines (World Health Organization, 1992) inserts self-inflected injury as disturbance caused by
Stereotyped Movements”, i.e., movements which are “voluntary, repetitive, stereotyped, non functional”, which can be subdivided into “self-in infliction” and “non self-in infliction. The first group includes repeated head-hitting, slapping, eye-hitting, hand, lip, body- biting.

According to DSM-IV-TR there doesn’t exist a “typical” age or modality for the initial disturbance of stereotyped movement, of which self-infliction is integral part. Besides this, reference is made to the fact that localization of this behavior is modified through the years (American Psychiatric Association, 2000).

Various studies have shown that there is an initial phase of SIB during childhood (Oliver, Murphy, & Corbett, 1987; Keuthen et al., 2001).

Other studies (Rojahn, 1986; Kahng, Iwata, & Lewin, 2002) have shown that more frequent forms of self-infliction are: head and body-hitting, self-biting, skin-picking, scratching the body, self-pinching.

Additional studies have tried to reveal the locations that are most often object of self-infliction. It appears that such zones are distributed irregularly on the human body and more often on the head and hands. In the specific case of the head, the area most frequently hit seems to be the face, and on the back of the hand. The other zones are distributed on the back and lower arms, as well as the back of the legs (Symons & Thompson, 1997).

Self-infliction can be a psychopathological characteristic frequently associated with diverse syndromes with multiple etiology.

Among the syndromes in which the presence of SIB has been indicated we will discuss the Prader-Willi Syndrome the Down Syndrome, and Autism.

1.1 Prader-Willi Syndrome

The Prader-Willi Syndrome (PWS) is caused by the deletion in the 15q11-q13 region of chromosome 15 of paternal derivation.

The distinctive characteristics of PWS are hypotony, obesity, hypo-go- nadism, intellectual disability, mood instability, temper tantrums (Clarke, Boer, Chung, Sturme, & Webb, 1996; Plantin, Milochau, Broussine, & Blondin, 1997; Symons, Butler, Sanders, Feurer, & Thompson, 1999; Campeotto, Naudin, Viot, & Dupont, 2001; Whitman, Myers, Carrel, & Allen, 2002). In literature it has been reported that subjects with PWS show severe self-infliction with a prevalence that varies from 70% to 90% (Symons et al., 1999; Wigren & Heimann, 2001; Buono, Palmigiano, & Scannella, 2005).

Symons et al., (1999) have revealed that the most common form of self-infliction is skin-picking that is manifested in 69% of young people with PWS and 81% of adults. The head (42%), legs (40%) and arms (39%) are the body areas most often hit, and in particular the rear areas. The Authors do not seem to have noted differences correlated to gender in relation to the number of parts hit. Adults frequently hurt themselves in more than one area of the body.
In a sample of subjects with PWS and intellectual disability, Buono et al., (2005) have reported that 73% initiated self-injurious behavior.

Wigren and Hansen (2003) have outlined that there exists a co-existence between compulsive and self-injurious behavior, more frequently with skin-picking and hair-pulling. Other authors have also discussed this concordance of factors (Stein, Keating, Zar, & Hollander, 1994). The authors identify skin-picking in a specific compulsive dimension.

Dimitropoulos, Feurer, Butler and Thompson (2001) have shown that in a sample of 105 subjects with PWS, a third put into act SIB of a skin-picking type, coherent with data originating from literature; while the relationship between chronological age and skin picking is not confirmed.

Subjects with PWS derived from uni-parental disomy show diverse behavioral dysfunctions among which is SIB manifested through some habits, as skin-picking and nail biting. People with PWS derived form deletion are predisposed to initiate SIB of the type: skin-picking, nail-biting, hair-pulling. According to the animal model of compulsive SIB, serotoninergic and dopaminergic mechanisms assume an important role (Dykens, Cassidy, & King, 1999).

1.2 Down Syndrome

Down syndrome is the most common genetic cause of intellectual disability, occurring in approximately 1 in 700 live births (Centres for Disease Control and Prevention, 2006).

Ninety-eight percent of cases of Down syndrome are caused by an extra copy of chromosome 21 (Trisomy 21) (Hassold & Sherman, 2002).

The DS is one of the most frequent causes of intellectual disability. It can be recognized at birth for its phenotypic characteristic to which can be added delay in psychic-motor nerve growth, Intellectual Disability at a different level, cardiopathy, epilepsy, breathing pathologies, behavioral problems, hard-headedness, emotive disturbances, dementia (Korenberg, Chen, Schipper, Sun, Gonsky, Gerwehr et al., 1994).

As for phenotypic aspects, subjects with DS can be characterized by their naturally warm and a generally peaceful nature and ability to mimic others (Menolascino, 1965; Gibbs & Thorpe, 1983). But sometimes behavioral problems such as aggressiveness, and highly pronounced hyperactivity may be present (Menolascino, 1965, 1967; Gath & Gumley, 1984; Myers & Pueschel, 1991; Cuskelley & Dadds, 1992).

In literature, a prevalence of 25% comorbid psychological disturbances is forecast, even if the data varies at diverse levels. Behavioral disturbances are diagnosed in over 10% of children. The same percentage is revealed for attention/hyperactivity deficit, mood disorders, association with autism and infantile psychosis (Menolascino, 1965, 1967; Gath & Gumley, 1986; Howlin, Wing, & Gould, 1996). Several authors have emphasized a difference due to gender for vulnerability to psychopathological problems (Menolascino, 1965; Gath & Gumley, 1986).
Literature presents examples of cases that show multiple SIB that affect various regions of the body; i.e. hitting the eyes, generating contusions and lacerations hitting the head, body, face, ears with the hands, and also hitting the head toward object. The body areas more greatly affected by the SIB syndrome seem to be: lip/mouth, hands, head, and cheek.

Mazaleski, Iwata, Vollmer, Zarcone and Smith (1993) have determined the body areas affected by SIB to be hands and face.

Fisher, Bowman, Thompson, Contrucci, Burd and Alon (1998), in a study conducted on a boy with Down Syndrome, profound intellectual disability and severe SIB, have shown that the area affected was around the ears. The resulting SIB was repetitively and continually hitting the ears resulting in contusions and lacerations, and was produced once the subject had woken up.

Hagopian, Paclawskyj and Kuhn (2005) have examined the SIB behavior of a person with SD and profound intellectual disability. The areas affected were the eyes, with a definite action of eye poking. The SIB produced over time a separation of the retina.

Määttä, Tervo-Määttä, Taanila, Kaski and Iivanainen (2006) demonstrate the presence of SIB in 3% of the DS group under analysis. The SIB was associated with a clinical context of DS and severe intellectual disability. The body areas most affected were the head and ears. The resulting action was to hit and twist the ears with the hands. The resulting damage was severe. The authors have discussed the significant difficulties in treating severe forms of SIB.

Other studies have demonstrated the presence of behavioral problems such as SIB and precocious dementia in subjects with SD (Hirayama, Kobayashi, Fujita, & Fujino, 2004).

1.3 Autism

Autism Disorders (AD) is characterized by a significant qualitative and quantitative mixture of deficits. In the majority of cases this is associated with intellectual disability at a different level (American Psychiatric Association, 2000; McCracken, McGough, Shah, Cronin, Hong, Aman, et al., 2002).

Various studies (Lewis & Bodfish, 1998) have demonstrated that in AD the prevalence of SIB varies from 30% to 69% (Schroeder, Schroeder, Smith, & Dalldorf, 1978; Bodfish, Symons, Parker, & Lewis, 2000).

Some studies have also demonstrated that in subjects with DA the areas most affected are the head, the hands and legs. The SIB behavior most represented is hitting oneself and self-biting (Symons, Hoch, Dahl, & Comas, 2003; Moore, Fisher, & Pennington, 2004). In a sample of 102 persons with AD, 49% of participants showed SIB behavior (Ballaban-Gil, Rapin, Tuchman, & Shinnar, 1996).

According to Baghdadli, Pascal, Grisi and Aussilloux (2003), persons with AD may develop SIB in severe forms. The factors that favor the
growth of SIB have been identified as lacking ability for autonomous action and managing daily life, besides the severity of the autism. Retarded language development and difficulty in interpersonal relationships are not considered risk factors.

Moreover, Murphy, Hall, Oliver, and Kissi-Debra, (1999) and Bodfish et al. (2000) have found that young age and a severe level of intellectual disability are not to be considered risk factors in developing SIB in association with DA.

Canitano (2006) conducted a study on a sample of 11 people with AD and a moderate or severe ID. All subjects presented SIB. The typologies more commonly present were head-hitting and hand-biting.

2. Aim of the study

Our study was conducted with the aim of analyze SIB in a sample constituted of subjects with differing clinical syndromes associated with ID, to reveal similarities and differences among syndromes, inherent in body localization and typology of SIB.

3. Sample

The sample was composed of 84 persons with ID (10 PWS, 25 DS, 49 AD) selected among a wider sample constituted of 1040 persons with ID. The percentage of persons with SIB within each syndrome was 55.5% in PWS group, 45.4% in DS group, 70% in AD group.

The chronological age of the participants varied from one to 47 years of age. The PWS group consisted of 6 males and 4 females, the average age is 14.3, $SD = 7.4$. The DS group was composed of 16 males and 9 females, with average age of 15.3 years, $SD = 10.6$, while in the autism group the males were 29, and females 20, with an average age of 13.1 years, $SD = 8.5$.

All subjects presented intellectual disabilities of various grades of intensity according to DSM-IV TR criteria (American Psychiatric Association 2000).

In the PWS group, 70% of subjects show mild ID, and 30% moderate. Subjects with DS are distributed in a more differentiated manner: 20% present mild IDs, 28% moderate, 44% severe, 8% profound. In the AD group, 18% had mild ID, 14% moderate, 44% severe, 24% profound.

4. Methodology

The SIB have been identified and assessed through application of a Self-Injurious Behavior Schedule (SRCA) administered, by specifically quali-
fied psychologists, to families and counselors of the observed persons, who were present in the rehabilitation wards and receive diagnostic services at the IRCCS Oasi Maria SS, Troina, Italy.

The diagnostic instrument has been previously devised and validated with the aim of revealing the presence of SIB; besides this, it is capable of discriminating between diverse topographical areas and can identify the frequency of emission and intensity of SIB. The subject’s age at the moment of first SIB outbreak was also recorded.

The psychometric properties of the SRCA were assessed in a sample of 40 people with ID (Buono, Palmigiano, Scannella, & Di Nuovo, 2006). Inter-rater reliability was computed applying the schedule on single individuals on the part of two counselors.

The percentage of concordance between the two counselors resulted very high (equal to 92.33%); Cohen’s $k$ was .60. As regards the concurrent validation, the schedule was compared to the subscale “SIB behavior” of the AAMD test (Nihira, Foster, Shellhaas, & Leland, 1975); the percentage of concurrence between the two scales was 85%, with $k$.65.

Informed consent has been obtained by the families of the interviewed subjects.

5. Results

The data collected in our sample demonstrate that SIB is present in all three groups taken into consideration, and that first indication of SIB (table 1) is prevalent in early infancy (<7 years). In particular in subjects with PWS, in 90% of cases SIB emerges in the above-mentioned age range; 72% for persons with DS, similar to subjects with AD (72%). In the age group 7-12 years, PWS has a SIB percentage of 10%, DS 12%, AD 10%.

<table>
<thead>
<tr>
<th>Beginning age</th>
<th>PWS</th>
<th>DS</th>
<th>AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;7</td>
<td>90%</td>
<td>72%</td>
<td>72%</td>
</tr>
<tr>
<td>7-12</td>
<td>10%</td>
<td>12%</td>
<td>10%</td>
</tr>
<tr>
<td>13-18</td>
<td>0</td>
<td>4%</td>
<td>6%</td>
</tr>
<tr>
<td>&gt;18</td>
<td>0</td>
<td>12%</td>
<td>8%</td>
</tr>
<tr>
<td>Not valuable</td>
<td>0</td>
<td>0</td>
<td>4%</td>
</tr>
</tbody>
</table>

Table 1 - Distribution of sample according to the beginning age of SIB symptoms
Relative to the bodily areas affected by SIB (table 2) the distribution in the three syndromes is as following:

In the group of persons with PWS bodily areas most affected by SIB are hands (90%), arms (70%), legs (70%), mouth and head (30%), nose, cheeks, ears (20%). Persons with DS present SIB on the mouth (48%), hands (44%), head (29%), cheeks (12%), ears (8%).

In persons with DA the SIB is localized prevalently in the hands (55%), mouth (45%), head (39%), cheeks (37%), neck (16%), forehead and arms (12%).

As shown in table 2, the differences among groups in localization are statistically significant for hands and arms (both prevalent in PWS).

Tabella 2 - Localization of SIB, differences among groups, and levels of significance to χ² test

<table>
<thead>
<tr>
<th>SYNDROMES</th>
<th>PWS</th>
<th>DS</th>
<th>AD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N°</td>
<td>%</td>
<td>N°</td>
</tr>
<tr>
<td>forehead</td>
<td>1</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>nose</td>
<td>2</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>cheek</td>
<td>2</td>
<td>20</td>
<td>3</td>
</tr>
<tr>
<td>ears</td>
<td>2</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>eyes</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>mouth</td>
<td>3</td>
<td>30</td>
<td>12</td>
</tr>
<tr>
<td>head</td>
<td>3</td>
<td>30</td>
<td>5</td>
</tr>
<tr>
<td>nape</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>neck</td>
<td>1</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>hands</td>
<td>9</td>
<td>90</td>
<td>11</td>
</tr>
<tr>
<td>legs</td>
<td>7</td>
<td>70</td>
<td>0</td>
</tr>
<tr>
<td>arms</td>
<td>7</td>
<td>70</td>
<td>0</td>
</tr>
</tbody>
</table>

As far as SIB typology is concerned (table 3), its most common manifestations in PWS are skin-picking (50%), nail picking-eating (40%), hair-pulling (30%), self-scratching and finger-object in cavities (20%)

People with DS most frequently manifest grind teeth (32%), hand hitting (28%), pick-eat nails (24%) self-biting, body-object hitting; insert finger, objects in cavities (12%).

In persons with AD the SIB most frequently manifest is hand-hitting (41%), object hitting (41%), self-biting (39%), finger-object in cavity (35%).

The significant differences among groups are shown in table 3.
6. Conclusions

The data reported indicate, in reference to PWS, that in our sample the SIB with the most frequent occurrence is skin-picking (50%) with similar results in other studies (Symons et al., 1999) even if our percentages result lower. Wigren and Hansen (2003) have reported in their research, besides skin-picking, pulling hair as a SIB characteristic frequent in subjects with PWS. In our sample this behavior is present in 40% of cases. Other studies (Dimitropoulos et al., 2001) have shown the presence of the behavioral characteristics referred above. Concerning body location of SIB, our data confirm the topographical areas most frequently involved as the hands, legs, arms and head.

In our sample with DS the SIB most frequently results in teeth grinding, eating nails, body-hitting with the hands. Our data, in this case, are not in agreement with that reported by other authors.

Fisher et al. (1998), Hagopian et al. (2005) and Määttä et al. (2006) have shown that in subjects with DS, when SIB is present, more frequent characteristics are eye poking, hitting and turning the ears with the hands. This result is not confirmed by our sample. Regarding bruxism and onicofagy, behaviors about which literature is discordant on whether to consider them self-injury behavior, our opinion is to consider them in a broad definition of...
SIB, generally understood as behavior that causes or could cause physical harm.

Symons et al. (2003) and Canitano (2006) in their studies indicated “self-biting” and “hitting oneself” as SIB more frequent in AD. Our data are in only partial agreement with this, as far as considering this behavior present respectively in 39% and 41% of cases reported, while a similar percentage (41%) is reported for body-object hitting, and 35% for “finger/object in cavities”.

Relative to specific body areas, as in the previously cited studies, also in our sample there is a prevalent involvement of the hands, head, face, and arms.

In literature it has been reported that an insurgence of SIB occurs frequently during early childhood (Oliver et al., 1987).

Our analysis has shown that the range of age in which SIB emerges coincides in all three syndromes, and may be identified in the age range between 0 and 6 years (90% for PWS, 72% DS, 72% AD). The same coincidence between syndromes has been shown for the range from 7 to 12 years (10% for PWS, 12% DS, 10% AD).

To explain differences, we should consider that a wide-range definition of SIB reveals a series of behavioral symptoms that are not unanimously agreed-upon by researchers as signifying SIB. Some of them could be considered part of other psychopathological conditions, as for example the obsessive-compulsive spectrum.

References


Inclusive education: a qualitative leap*

_Elena Tanti Burlo*¹

Abstract

This article aims at joining the debate triggered off by Vianello & Lanfranchi’s (2009) article published in Life Span and Disability, 12 (1), 41-52. The Author highlights the situation of Inclusive Education in Malta and backs Vianello and Lanfranchi’s hypothesis that children with intellectual impairment gain more when educated in ordinary settings.

The importance of implementing inclusive education in a ‘good enough’ way with ordinary teachers fully engaged with all their students, including those with intellectual impairment, has been highlighted.

The Author discusses the importance of empowering and supporting educators to include all their students in their ordinary classrooms and providing them with the necessary support, without creating structures which could lead to the teacher’s disempowerment and the students’ segregation and eventual exclusion.

If inclusive education is such a powerful tool for the development of children, not educating children in an inclusive environment could be seen as an abuse (an educational system’s abuse) on the children whose development it is duty bound to facilitate.

Keywords: Inclusive Education, Empowering Teachers, Peer Preparation Programmes, Educational Systems

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1. Introduction

Vianello and Lanfranchi (2009) suggested that Italian children with intellectual impairment due to genetic syndromes (students with Down syndrome, Williams syndrome, Prader Willi syndrome, Cornelia de Lange syndrome and Fragile X syndrome) assessed on psychometric tests seem to surpass the estimated projected development said to be imposed by their congenital condition. The authors also noted that the scores obtained, on various psychometric tests, by the Italian sample are higher than those found in international literature. These students seem to overcome, to a certain extent, the barriers of their congenital, ‘physical limitations’ or their ‘deficits’ and develop what may be called ‘surplus’. The authors have indicated that this ‘surplus’ in Italian children with intellectual impairment could be the result of inclusive education.

Vianello and Lanfranchi’s (2009) results are indeed very interesting. The effects of inclusion, when implemented in a ‘good-enough’ way, to steal Winnicott’s famous words when he was referring to the ‘good enough mother’, may have positive effects on the cognitive, social, emotional, aids to daily living, level of self determination and quality of life.

Where does Malta stand with regard to inclusive education practices?

Meijer, Soriano and Watkins (2003) sustain that the present trend of the politics of education in Europe is moving towards the inclusion of children with disabilities and learning difficulties in ordinary schools with the necessary support for teachers from additional staff, teaching materials, in-service training and the appropriate technology. On the basis of the level of inclusive practices Meijer et al. (2003), divide different countries according to three categories:

- The uni-directional approach, where the majority of students are included in the same school thus offering one educational system with a variety of services focused at school. These countries include Spain, Greece, Italy, Portugal, Sweden, Iceland, Norway and Cyprus.

- The multi-directional approach is said to offer a myriad of approaches for the integration of children with disability and learning difficulties between mainstream and special schools. Countries applying this system are Denmark, France, Ireland, Luxemburg, Austria, Finland, England, Lithuania, Liechtenstein, Czech Republic, Estonia, Poland and Slovenia.

- The third category is the bi-directional approach which has two distinct educational systems: one type of school for typically developing children and the other for those with a statement of educational needs needing extra support. Students would attend either a special school or special classes in ordinary schools where they would not have access to the ordinary curriculum. Switzerland and Belgium adopt this system.

Until a few years ago I was convinced that the Maltese experience fitted in the multi-directional approach as there was an ever increasing trend to-
wards inclusive school practices and, therefore, towards the uni-directional approach. However, more recently, with the publication of various ministerial documents like: “For all children to succeed: A new network organization for quality education in Malta” (2005), “Inclusion and special education review” (2005) and, more recently, “Special schools reforms” (2009), the momentum and investment, in my opinion, has been shifted toward a more segregated education through the use of resource centres (formerly known as special schools), and learning zones as indicated in the reform which states that when the students’ ‘relative (academic) levels (were) not improving as expected, new learning zones will be set up within the mainstream secondary school. Students still not achieving the desired results may attend an out of school learning centre where specifically designed short and long term educational programmes will be offered. These new facilities can also provide an education for students showing significantly challenging behaviour’ (Ministry of Education, Youth, Employment, 2005c, p. 44). Nurture rooms and groups have also been set up in primary schools for children with challenging behavior and children with disability are often taken out of class to work on a one-to-one basis in resource rooms. The reform ‘will work towards the reintegration of students from learning zones and learning centres into the mainstream education system,’ (Ministry of Education, Youth, Employment, 2005c, p. 44) and is seen, by the Educational Authorities, as a way to ‘further consolidate the principle of inclusion’ (Ministry of Education, Youth, Employment, 2005c).

The system, therefore, lately, seems to give greater importance to investing in these segregating structures and strategies rather than in truly inclusive schools.

On my visits to Italian schools, accompanying Maltese masters students, the Italian teachers we met give a clear message: children with disabilities are teachers’ responsibility like the rest of the students. They have the right to be educated with their peers. Segregation, in whatever form, is not an option. All children have the right to be educated with their peers and we therefore work on how best to include all students in our classrooms both with regard to the accessibility to the general curriculum as well as socially. Obviously the schools we visited were state of the art schools where educators were greatly supported. An excellent example are the schools we visited in Modena which are supported by MEMO (Multicentro Educativo Modena ‘Sergio Neri’).

Maltese inclusive education is still often seen as ‘the integration of children with disability’ and not as the philosophy underpinning all educational practices, although the National Minimum Curriculum (Ministry of Education Youth, Employment, 1999a, 1999b) highlights various principles like, for example:

- principle 1, ‘quality education for all without undermining the principles of solidarity and co-operation’;
- principle 2, ‘respect for diversity’;
- principle 8, the state should provide ‘an inclusive education’ fully ac-
 knowledging individual differences and ‘to professing as well as imple-
 menting inclusionary politics.’

The fact that the document talks about inclusive education ranking this
principle as eighth could be interpreted that inclusive education is seen as
an appendix and not as the underpinning philosophy of education.

Within this scenario, and the absence of a strong united movement
which advocates for inclusive practices by parents and professionals, in-
cluding educators and researchers, the educational authorities are finding it
easier to create opportunities to be able to either move children out of or-
dinary schools and into special schools, and this sometimes happens after
the primary school and more so at post secondary level, or having the stu-
dents spend time in resource rooms, learning zones, resources centres or by
actually encouraging the parents to send their children to special schools
from the very beginning. The educational authorities emphasize the part of
the Salamanca Statement which states that “special schools or units within
inclusive schools may continue to provide the most suitable education for
the relatively small number of children with disabilities who cannot be ade-
quately served in regular classrooms or schools” (Salamanca Statement,
UNESCO, 1994). The working group set up by the Ministry of Education,
Youth, Employment (2005) reinforces this as they believe that there are
children who ‘would gain more in a selective set-up and environment’. Who
is going to decide this? (Tanti Burls, 2007). The answer, as anticipated, is
given by the Special Schools Reform (Ministry of Education, Youth, Em-
ployment, 2009). ”It is being recommended that a team of professionals
(henceforth ‘Team’) is set up in order to evaluate the referrals and advise
parents which educational institution is best suited for the particular stu-
dent with a statement of needs” (Ministry of Education, Youth, Employ-
ment, 2009, p. 20).

And once again, although the document ‘For all children to succeed: A
new network organization for quality education in Malta’ (Ministry of Ed-
ucation, Youth, Employment, 2005b) states that ‘Inclusive education is the
ideal model of education’ the document goes on to declare that ‘people are
not ready for it’ without adequate scientific backing. To be fair, this docu-
ment, as well as that on the Transition from primary to secondary schools
(Ministry of Education, Youth, Employment, 2007b) have eliminated
streaming, in State schools, from the age of nine years and introduced one
secondary school, replacing two separate schools where students were ad-
mitted according to their examination results. However, although all chil-
dren will now be attending the same secondary school they will be selected,
set, divided, according to their abilities in the core subjects. The introduc-
tion of this setting has been indeed heavily criticized by many academics, as
there is no strong evidence that this will improve all students’ academic
performance. On the contrary it is actually those struggling students who do worse in such a system and who develop a lower level of self esteem (Hal-lam, 2002). Setting will not, in the long run, diminish the level of stress all stakeholders have been worried about even for children in the higher sets. What is even more worrying is that most children with disabilities and those who lack basic literacy and numeracy skills are being grouped together thus creating segregated differentiated classrooms, called foundation classes, which do not enhance inclusion and facilitate the development of a low level of self esteem.

2. Inclusion within a highly selective educational system. How did it all begin?

The first systematic attempt at including children with disabilities in Malta (children with disabilities were ‘mainstreamed’ in ordinary schools since the early 80’s), was made at the end of 90’s through an Action Research Project called Including the Excluded. The importance of training teacher-facilitator teams together and the implementation of the peer preparation programme were evaluated. The joint project was coordinated by the University of Malta, Institute for Child Development, now the Programme for Inclusive Education, in collaboration with the Eden Foundation and under the consultancy of the University of Padova (Tanti Burlò, Soresi, Nightingale, & Xuereb, 1997).

The project team worked around and within a strong exclusive educational philosophy, however, notwithstanding this strong culture of segregation, many children with disability were able to experience positive school life alongside their typically developing peers. To date, we can safely state that many students with diverse needs have benefitted from attending ordinary schools.

Teachers and facilitators - now called Learning support assistants, paraprofessionals in the U.S. (while they, now, undergo a two year university “evening part-time course” in Facilitating Inclusive Education or its presumed equivalent) together attended training sessions discussing issues on inclusive education, setting teaching objectives and individual educational programmes, collaborative teaching, the implementation of peer preparation programmes and assessing the level of inclusion through sociometric testing.

Five boys and two girls aged between 5 and 10 years were involved in this project. Five of these children were ‘graduates’ from Eden Foundation’s early intervention transdisciplinary programme. The inclusive group was compared with a control group. The effects on the level of inclusion and the children’s adaptive and academic progress were evaluated by means of (a) sociometric tests, (b) the administration of the Vineland Adaptive Be-
haviour Scales (Sparrow, Balla, & Cicchetti, 1984) and (c) the classes’ academic reports.

a. Level of inclusion: sociometric tests

These were by far the most interesting findings and ‘this is to the credit of those teachers and facilitators who have managed to develop a new and dynamic relationship between themselves and their pupils’. The children with disability in the inclusive class (the experimental group) were selected more often by their peers to be in their group than the designated child, with learning difficulties, in the control classes. Children in the inclusive classes also ‘showed less indications of rejection than the control class (Tanti Burlò et al., 1997). These results were the same as those obtained in a later study by Cuschieri (1998).

Worth mentioning ‘are the results obtained in the two classes where the facilitating programme for inclusion were not implemented and where the facilitator was not utilized as an integrating, inclusive force. In both classes, the total amount of actual choices and rejections given by the children are very limited indicating that the children in those classrooms have not formed many meaningful relationships with their classmates’.

On deeper analysis of the sociometric results it became evident that children in the experimental classrooms were more in tune with each other’s feelings and they ‘guessed’ more accurately who would select them and who would least like to be with them. This shows a very developed sense of emphatic understanding in the experimental group. ‘This is surely the primary aim of any educational system’ (Tanti Burlò et al., 1997).

Vianello and Moalli (2001) maintain that direct experience of relating with a peer with disability is of utmost importance for the development of positive attitudes. The amount of time spent together is also an important facilitating factor although adequate training may also have it’s positive effects as shown by Tanti Burlò et al., (1997) and Cuschieri (1998).

b. Adaptive behaviour

The children with disability in the inclusive classrooms improved in all the domains assessed on the Vineland Adpative Behaviour Scale (Sparrow et al., 1984), that is, communication, socialization, daily living and motor development. Dramatic improvement was evidenced in most children especially in the area of communication. The results are confirmed by the comments of the parents who stated ‘that their children were speaking more clearly and that they are being understood by many more people outside the family circle’ (Tanti Burlò et al., 1997).

Vianello (1990) had also confirmed that students with disability attending ordinary schools tend to have more developed social skills, which is reflected in the amount of chores they do and in the way they communicate and socialize. The adaptive behaviour of students in special schools were al-
so found to be less developed than those attending ordinary schools (Buckley, Bird, Sacks, & Archer, 2002).

Maltese adolescents with Down syndrome attending special school, after having attended inclusive schools, scored low in autonomy skills when compared with an Italian group of youngsters with Down syndrome, who attended ordinary schools and a community based programme for autonomy run in Rome (Micallef, 2006). Students who are transferred to special schools from ordinary schools seem to regress and loose a lot of their skills (Buckley et al., 2002) This is also being said and highlighted locally by some parents especially with regard to communication skills. However this needs to be further researched.

c. Academic progress

Contrary to the opinion of many educators and parents at the time of the initial project, the results showed that the other’s students academic progress did not suffer because of the child with disability.

3. What could be considered to be the essential ingredients for successful inclusion?

Advocates for inclusive education were heavily criticized for the reason that children with disability should have not been allowed to attend ordinary schools before the teachers were properly trained to teach them. Over 25 years have passed and the same arguments remain dominant. It has become more and more evident that the successful inclusion of a child with disability, and of all children at that, depends on the learning environment the children are immersed in. Vianello and Moalli (2001) state that ‘a good way for preparing oneself for inclusion… is to begin to do it’ (p. 39) with schools and educators who would welcome and engage themselves with all students in a mixed ability environment, implementing universal design for learning, supported by strategies for cooperative teaching and learning. Cooperation and planning, especially person-centred planning techniques like MAPS (Mapping an Action Planning System) and IEPs (Individual Educational Programmes) for smooth transitions, enhancing self-determination and a better quality of life (Tanti Burlò, 2007a)

4. Present situation in Malta

4.1 The students

“It is estimated that 0.36% of the total student population attend special schools” (Ministry of Education, Youth, Employment, 2009, p. 13). The following data clearly shows the ever increasing amount of children who are
being identified as having ‘a statement of educational needs’. Before presenting that data some general demographic data: Malta has a population of 404,962, with a birth rate of 3,825 per annum. In the same year, the individual with disability were 712 in the age bracket 0-9 years, 1109 in the range 10-19 years (Census, 2005).

For students to receive extra support at school they have to have a ‘statement of needs’ drawn up by a psychologist. This report is presented by the school through the parents to the Statement Moderating Board. Requests for extra support have been increasing steadily year after year.

As the above Table 1 indicates, there has been a sharp increase in the amount of students assessed with a ‘statement of needs’. A breakdown of the amount of students in special schools shows an interesting pattern with almost a half of these students being over sixteen years of age. If we were to remove the 100 students within the 16+ age bracket the percentage of students with a statement of needs in Special Schools would be only 5.6% (Table 2).

<table>
<thead>
<tr>
<th>Table 1 - Students with a statement of needs in Malta, 2000-2009</th>
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<tbody>
<tr>
<td><strong>Type of school</strong></td>
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<tr>
<td>Normal school</td>
</tr>
<tr>
<td>Special school</td>
</tr>
<tr>
<td>Total</td>
</tr>
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Note:
(1) National Minimum Curriculum (Giordmaina, 2000, p. 27)
(2) Data calculated from Inclusive and Special Education Review (Ministry of Education, Youth, Employment, 2005) pp. 22-23
(3) Data taken from Special School reform (Ministry of Education, Youth, Employment, 2009)
(4) Personal correspondence with Special and Inclusive Education Network (05.01.2010)

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<table>
<thead>
<tr>
<th>Table 2 - Students in special schools according to age 2008/09</th>
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</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
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<tr>
<td>Numbers</td>
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Data taken from Special School reform (Ministry of Education, Youth, Employment, 2009) p. 10
There is, however, today, a growing trend to encourage parents of children with physical and or multiple disabilities either to send their children to special school for the whole week or to divide their week between ‘normal’ school and the resource centre. Parents and educators are attracted by the equipment, like the multisensory room, hydrotherapy pool and health care staff in the school.

The numbers in the schools for children with intellectual impairment have indeed dwindled. However, I suspect, that these numbers will begin to rise again, especially those of students over sixteen years of age since one of the resource centers (special schools), with the new reform, is now hosting students from 16 onwards. Many of these students would have attended ordinary schools till the age of sixteen after which they find themselves faced with very limited options for inclusive education (Equal Partners Foundation, 2007). In fact a post secondary school which had very successfully begun to welcome students with intellectual impairment has from this year closed it’s doors to students who do not have a certain level of academic achievement. This is indeed a pity as students with intellectual impairment and their parents were full of praise for the positive experience they had lived.

There does not seem to be clear cut criteria for determining who can receive extra support, what type, to what extent and where.

It would be interesting to investigate the socio-economic background and level of education of parents of students attending special schools today, especially those at primary and secondary levels. Research conducted in 1992 in special schools showed that the level of the parents’ education was rather low with the majority of them only having frequented till primary school level. It was not only the type and extent of disability which determined whether a child went to a special school or not (Tanti Burlò, 1992).

5. Supporting and consolidating good practices

We have managed to get most students in, more or else, inclusive settings and it is now important to support good practice, consolidate it and increase it so that all students will attend ordinary schools from the beginning and remain there without being taken out on a regular basis or even segregated in any way away from their peers.

5.1 Early Intervention and inclusive education

Before the beginning of the 90’s early intervention was given on an ad hoc basis available only on an individual private basis. The collaboration between the University of Malta and the Eden Foundation saw the birth of important community based programmes, the Early Intervention Pro-
gramme and the Inclusive Education Programme. A transdisciplinary team was developed to support the early intervention of children identified with intellectual impairment. The children’s progress was impressive. With the focus on a total means of communication programme (the use of flash cards with the written word, the verbal word accompanied by signing) around the development of motor, social and self-help skills, this spearheaded the children’s level of communication, their engagement in the world around them, their level of self-determination and consequently, their quality of life. Parents saw that their children could learn and that they could learn a lot, much more than they ever expected. Graduates from the Early Intervention Programme attended kindergarten with a great eagerness to be with others and to participate in what is going on around them. An off shoot of all the work done through total communication was the child’s ability to read. Many of our children with Down syndrome, for example, could sign to some 200 flash cards at the age of two and entered kindergarten with very good reading skills.

The positive effects of early intervention helped the children to be ‘integrated’ in ordinary schools. The parents were no longer satisfied with the practice, at the time, of having children with ‘special needs’ repeat the first two years of kindergarten to be then sent to a special school at age 6 or 7 because they were told that their child ‘would not be able to follow the set curriculum’, ‘would not benefit and become frustrated’ and that their child ‘would disrupt the other children’s learning’. The parents wanted their children to remain in their community or church school alongside their peers, part of their cohort community. The parents and professionals working with them were vindicated and saw the children flourish where inclusive practices were properly implemented.

There are presently three major entities offering early intervention. These are Equal Partners Foundation, INSPIRE (incorporating the Eden Foundation), and the CDAU (Child Development Assessment Unit). However, apart from the fact that not all programmes delivered are intensive and offered on a regular basis there are many children who still do not receive any early intervention services. Once again one needs to research on who is receiving the services and how regularly.

Buckley, Bird, and Sacks (2006) would agree with Vianello and Lanfranchi that profiles of children with Down syndrome can be changed with ‘good enough’ (my addition) practice of inclusive education. ‘The teenagers with Down syndrome who have been included in mainstream age-appropriate classrooms do not show a weakness in communication skills relative to their social and daily living skills’ (Buckley et al., 2006, p. 52). They further sustain that the gains obtained through early intervention greatly diminish if the children attend special schools and the effects are even more negative if the children attend ‘special classes’ in ordinary schools. These children ‘show the expected profile, with significant differences between
their communication, socialisation and daily living skills in the expected di-
rection’ (Buckley et al., 2006, p. 52) Parents have witnessed this and have
been articulating their concern with us. It is very worrying when a substan-
tial number of students are sent to special schools rather than being sent to
ordinary secondary schools with their peers.

Policy decisions need to be taken on evidence based strategies. Agius
Ferrante (2008), a teaching support consultant responsible for students’ ac-
cessibility to the general curriculum, in a primary and secondary church
school, co-ordinated an action-research project and revised the schools in-
clusive practices adopting an all school approach. First and foremost the
teaching support consultant is responsible for all the students’ accessibility
to the general curriculum, and her responsibilities are not restricted to
those students with a statement of needs; secondary, all teachers were made
responsible for all their students and thirdly the creation of ‘teaching teams’
between the class teacher and the L.S.A (Learning Support Assistant) in
the primary school and the subject teacher and subject L.S.A. in the sec-
ondary school That is, the school abandoned the usual practice (still adopt-
ed in state schools and many of the other schools) ‘for most facilitators
(L.S.A.s) to follow the same child/children for two to three years, while the
class moves onto another teacher annually’ (p. 75). Agius Ferrante calls this
a transition from ‘children-pegged support’ to a ‘team-pegged’ support
(teacher-facilitator) in the primary level and a ‘subject-pegged’ support at a
secondary level. The new approach was reviewed by all the stake holders,
teachers, facilitators, students and parents and the Author concludes that all
input from the various stakeholders in the school overwhelmingly indicates
that this new approach is superior and more effective in all respects. She
presents various quotes to emphasis the positive perception of this new ap-

A student: ‘The teacher and facilitator work better together’
A secondary school student: ‘Helps me more and the attention is on all of
us’

A parent, who does not have a child with disability: ‘Having students with
disabilities in the school is a very positive experience, both for the children
and for us parents. Personally it impacted me as a parent understanding dif-
ference and intolerance. The new experience is definitely reaching far more of
our students, supporting each student according to his needs, which after all is
the Lasallian charisma’

6. Educators’ perceptions and attitudes

In an ongoing research project called When educating becomes difficult
(Tanti Burlò, Camilleri, & Zucca, 2009) secondary school educators were
asked to identify situations when they found themselves in difficulty to
teach. This research showed that educators are more concerned about the ‘challenging’ behaviour of both the individual child and that of part of the class rather than difficulty in teaching. Also Vianello’s (1990) study, cited in Vianello and Moalli (2001), concluded that teachers are more prone to look at behaviour. ‘The more a student does not disturb, the more the student is accepted’ (p. 30).

Educators clearly indicated that they find it difficult to teach in low set level classes, low streamed classes and mixed ability classes. Children with disability are amongst the students in the low set, low streamed classes and mixed ability classes. These educators think that other educators are experiencing the same situation (Tanti Burlò et al., 2009).

When asked about different teaching techniques used many of the educators left this question out. The majority who did answer said that they often used frontal traditional style classrooms, grouped children according to their ability but also according to diverse abilities, said that they used differentiated and cooperative learning techniques. The majority said that they were not aware of universal design for teaching, mind maps and use of circle time in class. Only 15% of the teachers had said that they needed further training in teaching strategies (Tanti Burlò et al., 2009) and, in fact, ‘although the majority of teachers are not trained in IEPs no teachers applied to follow a course in designing IEP’s which was offered in 2002’ (Ministry of Education, Youth, Employment, 2005a, p. 58). When asked what type of school would they prefer to teach in, the majority said that they would like to work either in a girls secondary school for bright students with either streamed or set classes or in a co-ed streamed secondary school. Inclusive schools were not on many of their wish list (Tanti Burlò et al., 2009).

A lot of work still needs to be carried out to create a more positive environment for the development of schools to welcome children with diverse needs in every class having the teacher’s total ‘engagement’. Only 29% of the educators would like to see state schools turned into totally inclusive schools but at least only 10% were totally negative about having any resemblance of inclusive education.

Vianello and Moalli (2001) cite an earlier work by Vianello (1990) where he firmly upheld that teachers with a direct and engaging experience with students with disability would encounter less difficulties than an inexperienced teacher. The catch word, in my opinion, is ‘engaging experience’ that is, an experience by educators who took it onto themselves to make inclusion happen.

In a research project carried out by third year psychology students, on the perception of teachers in state and church schools indicated that educators in church schools have a more positive attitude towards students with disability than those in state schools (Vv. Aa., 2006). Where can we find the reason behind this discrepancy? Are teachers in church schools more ‘en-
gaged’ with their students with disability, as Agius Ferrante (2008) indicated? Do they feel that they receive more support?

Teachers are actually more supported by learning support assistants in state schools. In church schools the ratio between L.S.A. (*Learning Support Assistant*) and students with disability stands at 1:1.4 and in State schools the ratio is 1:1.26 (Tanti Burlò, 2007b). Do teachers in state schools have less opportunities to ‘engage’ with their students with disability as the learning support assistants take such an active role which could lead to the dis-empowerment of the teacher? Although, the teacher has full responsibility of all the children in the class (Ministry of Education, Youth and Employment, 2007b) not all teachers take on that responsibility. The system in the state schools is also offering alternatives for the student with disability to attend the resource room (in the primary school) the learning zone (in the secondary school) regular visits and days spent at therapeutic centres, leisure centres and resource centres (special schools). This situation, I believe, does not always facilitate the teachers’ ‘engagement’ with their students but might actually offer them the opportunity to opt out from supporting all the students in their class.

In Malta, the State education scenario is changing with the consolidation of educators having different roles such as: INCÔs (Inclusion Coordinators, modelled on the English SENCO, Special Educational Needs Coordinator), Learning Support Assistants and Specialized teachers. The INCO facilitates ‘links between Colleges and Resource Centres through networking activities’ (Ministry of Education, Youth and Employment, 2007a, p. 19) linked to both ordinary schools and resource centres; Learning support assistants, many of whom are untrained and at times their “inappropriate utilisation or excessive proximity…. has been linked to inadvertent detrimental effect (e.g., dependence, interference with peer interactions, insular relationships, stigmatization, provocation of behaviour problems” (Giangreco, Halvorsen, Doyle, & Broer, 2004, p. 82); and specialized teachers for children with literacy difficulties, challenging behaviour and other impairments. With resource rooms, in primary schools; learning zones, in secondary schools, together with the heavy investment we are seeing in the resource centres (formerly: Special Schools) all these are providing educators, in my opinion, opportunities for segregation.

This could be hindering the empowerment of the class teacher from taking full responsibility for all the children in class. Other options are presented to the teacher and the parents, options which are made attractive with expensive ‘toys’ like the multisensory room and more therapeutic segregated services presented as essential for the child’s improvement. “Some students with a statement of needs who attend mainstream schools may require services that can and are being offered in special schools. Such services include the use of the hydrotherapy pool, multi sensory rooms and specialised software and equipment such as communication aides that are
provided by special school” (Ministry of Education, Youth, Employment, 2009, p. 11) There is, therefore, a tendency to follow the medical model of disability so that many learning outcomes are ‘discipline specific’ and not ‘discipline free’ i.e. they are not learning outcomes “based on the educational needs of the student to assist him or her in pursuing valued life outcomes rather than the orientation of the various disciplines” (Giangreco, Edelman, Luiselli, & MacFarland, 1998, p. 4). If it is essential for the child to receive these services these should be either included during the student’s ordinary school life or offered after school. Working together, one can implement the role of the educator as defined by Ministry of Education, Youth and Employment’s (2007) Job Description Handbook through a model like VISTA which “gives the general educator an opportunity to assume ownership and responsibilities for teaching the student with disability” (Giangreco et al., 1998, p. 20). Apart from the teacher, the parent is ‘closely involved in decision-making’ and is seen as being ‘elevated as part of the team’ (Giangreco et al., 1998, p. 19-20). Service recommendations need to be educationally relevant and necessary and ‘only-as-special-as necessary’. Giangreco et al., (1998) believe that “the concept of only as special as necessary provided some families with an alternative way to think of what they wanted for their child” (p.18). This can also be true of the general education teacher and the rest of professionals involved with the child with disability.

What are therefore the implications of not educating children in inclusive schools with fully engaged teachers with their students and supported by a school based transdisciplinary team? Vianello (1990) and Vianello and Lanfranchi (2009) are convinced that if children with disability do not attend inclusive schools they will not develop ‘the surplus’ they describe and no change in the children’s profile will occur (Buckely, Bird, & Sacks, 2006). Can attending segregated services and education be seen as an added risk on the children perpetrated by the system, which is meant to provide for the development of their full potential? Could we call this ‘system added risk’ referring to ‘the further damage (psychological, social, physical) caused by the very same ‘caring system’ which is meant to intervene to create a facilitating environment for positive growth’ (Tanti Burlò, 1994, p. 43) of the child and family? It could well be.

Most of our Maltese children with disability are said to be attending ordinary schools. We now need to make sure that they are in inclusive settings, and remain there, learning with their peers with an empowered general education teachers equipped with the necessary teaching tools and supported by qualified personnel so that they will be fully engaged in the inclusion of all the children.

I have focused on Inclusive Education as providing that ‘good enough’ and facilitating environment where all children can be nurtured to their full potential, however, inclusive education is first and foremost a basic human
right for all children if we really believe that no child would be left behind in a truly inclusive participatory society.

As a conclusion I would report the story of Michael (fictitious name).

A few years ago we were supporting a boy, Michael, with multiple disabilities to attend his ordinary local school. His teacher and facilitators (learning support assistant) were perplexed because they thought that he would not be gaining from attending their school and needed a special environment, because, according to them, he needed special equipment. They had also visited the child who lived in an institution and found him to be asleep most of the time. They could not, at first, understand what benefit the child could receive from attending an ordinary school. We anticipated that they would have said that he needed to attend a multi-sensory room and this was arranged. He would attend a multi-sensory room once a week after school. Whether this affected his progress or not was really immaterial, the school was happy and the boy was taken on an outing. After three months I revisited the school and waited for Michael in his class. Michael was wheeled into the classroom asleep in his buggy. The children had already started their work. On entering the classroom all the children greeted him aloud, ‘Good morning Michael, Good Morning Michael!’ Their chorus woke him and he started to move. His teacher then put the computer on and he became more and more alert. The children related with him by first stating their name, Michael also has visual impairment, and telling him that they were going to touch his hand. The bell rang and the students came up to Michael, stated their name, and told him that “it’s break time so we’re off to the yard we go!”. And off they went …. With Michael of course. As the children played together his facilitator approached me, with a big grin on her face and with great satisfaction asked: ‘Do you like our multi-sensory room?’ As I looked around there was Michael surrounded by his friends who were talking to him, telling him that they were going to touch his face, that they were going to take him around the playground. They were singing together, pushing his buggy to and fro with the wind in his face and the sun shining on them all.

After the initial fear and hesitation all the school welcomed Michael and the head mistress, who was so sceptical about the usefulness of having Michael in her school stated that she never thought that it was the other children who were going to gain so much from their relationship with Michael.

That is not the end of the story. Michael lived in an Institution and his peers would visit him twice a week throughout the summer months. This has never happened with any of the other children living in the same institution but attending special schools. No children ever came to visit them. Michael had become part of their lives; he had become a significant person in their community. Michael is an example of excellent practice of inclusive education supported by a transdisciplinary team made up of members coming also from different governmental and non governmental agencies.
Unfortunately Michael is not at present attending school because of his deteriorating health. This is indeed very sad because his peers and school are still waiting to welcome him back amongst them (Tanti Burlò, 2002, pp. 124-125) And Michael? He is once again asleep…

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INSPIRE. http://www.inspire.org.mt/home


Micallef, C. (2006). We need the chance to be adults too! The acquisition of autonomy is a Human Right for every adolescent with Down syndrome. Unpublished dissertation. Malta: Department of Psychology, University of Malta.


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The text of the paper should clearly indicate the following sections (example for an empirical paper):
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2. Aims and hypothesis
3. Methods: Sample, Instruments, Procedure
4. Data analysis
5. Discussion

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Citations in the text should be indicated with the author's name, year of publication and page number, e.g.: Achinstein (1968, p. 32). A letter should be added to the year of publication if there are two references of the same author in the same year: Orne (1975a). According to APA norms, in the quotations with more than one author the symbol & should be used if the quotation is enclosed in parentheses (Estes & Skinner, 1940), otherwise "and" has to be used: e.g. Estes and Skinner (1940).

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