

---

# LIFE SPAN AND DISABILITY

Vol. XIII / n. 1 / January - June 2010

ISSN 2035-5963

Psychology  
Social issues  
Education  
Rehabilitation  
Habilitation

- The role of functional disability in psychiatric classification
- Inclusive school placements and surplus/deficit in performance for students with intellectual disabilities: Is there a connection?
- Evaluative Study on the social validity of the developmental disability parent training program Stepping Stones Triple P
- End-of-life decision-making: a descriptive study on the decisional attitudes of Italian physicians
- Mental retardation and reading rate: effects of precision teaching

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 the life, when specific existential events (e.g., adolescence, lost 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.life-span.it](http://www.life-span.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.

Editors in chief:

Santo Di Nuovo (Catania) / Renzo Vianello (Padova) / Serafino Buono (Troina)

International scientific committee:

• Valeria Abusamra (Buenos Aires) • Fredi Büchel (Geneva) • Gerhard Buettner (Frankfurt) • Raquel Casado Muñoz (Burgos) • Annick Comblain (Liège) • Vitor Da Fonseca (Lisbon) • Larry Dana (New York) • Douglas K. Detterman (Cleveland) • Monique Ernst (Bethesda) • Reuven Feuerstein (Jerusalem) • Sebastian Gaigg (London) • Carl Haywood (Nashville and New York) • Edward Janicki (Chicago) • Olga Jerman (Pasadena) • Mike Kerr (Wales) • Fernando Lezcano Barbero (Burgos) • Jean Louis Paour (Provence) • Ruth Luckasson (Albuquerque) • Michèle Mazzocco (Baltimore) • Susan Polirstok (New York) • Paul Probst (Hamburg) • Johannes Rojahn (Fairfax) • Jean Rondal (Liège) • Luis Salvador (Cadiz) • Elena Tanti Burlo (Malta) • John A. Tsiouris (New York) • David Tzuriel (Ramat-Gan, Israel) • Henny M J van Schrojenstein • Lantman-de Valk (Maastricht) • Benedetto Vitiello (Bethesda) • Patricia Walsh (Dublin) • Germain Weber (Wien) • Karl Wiedl (Osnabrück)

EDITORIAL BOARD:

Tommasa Zagaria (coordinator)

Maria Teresa Amata / Cinzia Bonforte / Santina Città / Francesco Di Blasi / Ada Natalia / Bernadette Palmigiano / Simonetta Panerai / Fabio Scannella / Marinella Zingale / Rosa Zuccarello

The english texts have been revised by Philip Doughty.

© Associazione Oasi Maria SS. - IRCCS / Città Aperta Edizioni  
All rights reserved





# LIFE SPAN AND DISABILITY

Journal promoted by the  
**Department of Psychology**  
Institute for Research on Mental Retardation and Brain Ageing "Oasi Maria SS." - Troina



© copyright 2010  
Città Aperta Edizioni s.r.l.  
94018 Troina (En) - via Conte Ruggero, 73  
Tel. 0935 653530 - Fax 0935 650234

Cover by Rinaldo Cutini

Published on line: June 2010

## Contents

The role of functional disability in psychiatric classification <i>Luis Salvador-Carulla &amp; Vladimir I. Gasca</i>	7
Inclusive school placements and surplus/deficit in performance for students with intellectual disabilities: Is there a connection? <i>Nancy L. Waldron &amp; James McLeskey</i>	29
Evaluative Study on the social validity of the developmental disability parent training program Stepping Stones Triple P <i>Paul Probst, Iain Glen, Julia Spreitz &amp; Florian Jung</i>	43
End-of-life decision-making: a descriptive study on the decisional attitudes of Italian physicians <i>Claudio Lucchiari, Marianna Masiero, Gabriella Pravettoni, Gianluca Vago &amp; Robert L. Wears</i>	71
Mental retardation and reading rate: effects of precision teaching <i>Francesca Cavallini, Federica Berardo &amp; Silvia Perini</i>	87





## The role of functional disability in psychiatric classification

*Luis Salvador-Carulla<sup>1</sup> & Vladimir I. Gasca<sup>2</sup>*

### Abstract

*Psychiatric functioning and disability have historically been considered separate from the broader disability field and have been measured differently than other medical conditions.*

*This paper provides an overview of the current concepts and international advances in the classification of psychiatric disability and explores the controversies and goals within the proposed systems.*

*It highlights key aspects of the role of disability and functioning in major psychiatric classification systems (including ICD-10/ICF, DSM-IV) and international programmes such as the Institutional Program for Psychiatry for the Person (IPPP) of the World Psychiatric Association. It stresses key studies on the impact of psychiatric illness in the overall functioning of individuals. Narrative review of studies providing details of key aspects of controversial issues is presented throughout the article.*

*ADL (Activities of Daily Living) and ICF (International Classification of Functioning) are two different models of disability which have different implications for the assessment of mental disorders. Within ICF, 'environmental' and 'personal' disabilities have been defined. In mental health, disability and functioning are part of two separate and theoretically complementary classification systems: the diagnostic system and its consequences on functioning and activity. Thus, a mental disorder may be determined by the level of dysfunction, particularly in DSM.*

*Although no system currently available properly captures the complexity*

\* Received: 26 February 2010, Revised: 20 May 2010, Accepted: 24 May 2010.

<sup>1</sup> Dept. of Neurosciences. University of Cadiz, Plaza San Marcos 6, Jerez 11403, Spain.  
E-mail: luis.salvador@telefonica.net

<sup>2</sup> Mount Sinai School of Medicine at Elmhurst Hospital Center. New York. USA. E-mail:  
vladimir.gasca@mssm.edu

*of the assessment of disability and functioning, the ICD-10 approach is conceptually more advanced than DSM-IV. Functional disability has significant implications in the holistic classification of mental disorders, particularly in the development of the World Psychiatric Association's IPPP programme.*

Keywords: Mental disability, Classification, Functioning, Quality of life.

## 1. Introduction

There is a lack of international consensus on the definition of health-related functioning and disability; which is regarded as an “elusive” concept in Medicine (Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006). However functioning and disability are domains of a key health construct to understand the relationship between the individual and the disease, where social support plays an effect modifier role (Prince, Patel, Saxena, Maselko, Phillips, & Rahman, 2007). Functional Status Indicators (FSI) provide as robust a prediction of health events as do complex comorbidity indices (Mayo, Nadeau, Levesque, Miller, Poissant, & Tamblyn, 2005), and the predictive power of disability exceeds that of clinical diagnosis in many chronic conditions. There is also a complex relationship between the construct of functioning/ disability and the construct of autonomy/dependency.

Paradoxically, modern psychiatry has paid little attention to functioning and disability relative to other medical disciplines. On the other hand, psychiatric disability has historically been considered separate from the broader disability field and it has been measured differently than in other medical conditions (Sanderson & Andrews, 2002). Recent studies using common measures have shown the impact of psychiatric disability compared to other causes of persistent functional impairment (Sanderson *et al.*, 2002; Alptekin, Erkoc, Gogus, Kultur, Mete, Ucok *et al.*, 2005). Mental disorders are a significant cause of disability and related global burden of disease. A 2005 report from the World Health Organization (WHO) on projection of the burden of disease showed that 31.7% of all years lived with disability are attributed to neuropsychiatric conditions, the four major contributors in this group being unipolar depression, alcohol abuse, schizophrenia, and bipolar depression (Mathers & Loncar, 2006). There is also a relationship between disability and use of resources; it is important to set up case-mix an other group of patients relevant to health planning (Boot, Hall & Andrews, 1997; Ruggieri, Leese, Thornicroft, Bisoffi, & Tansella, 2000). Compared to people with a physical disability, those with a mental disability require a different set of services to allow them to participate in the community and conduct their activities of daily living (Williams & Doessel, 2001).

Recent research underlines the complex interaction between mental health and disability; for example, depression is an important factor in the development and progression of disability in chronic medical conditions, while disability may influence the onset and continuance of depression (Kim, Stewart, Glozier, Prince, Yang, Shin *et al.*, 2007; Moussavi, Chatterji, Verdes, Tandon, Patel, & Ustun, 2007).

The aims of this review paper are: 1) to provide an update on the current concepts of functional impairment and disability, as well as their implications in psychiatry; 2) to review the role of functioning and disability in the main psychiatric classification systems (DSM and WHO family of classifi-

cation systems), and 3) to establish a relation between this construct and person-centred approaches in mental health and intellectual disabilities.

## 2. Methods

This review is part of the work carried out by the World Psychiatric Association (WPA) in its Institutional Program for Psychiatry for the Person (IPPP) working group to develop a person-centred approach in psychiatric diagnosis. We use an iterative process and round sessions to highlight key aspects of the major psychiatric classification systems in the area of disability such as ICD-10 (WHO, 2007), DSM-IV (APA, 2000), GLAP (Latin American Guide of Psychiatric Diagnosis - Guía Latinoamericana de Diagnóstico Psiquiátrico, APAL, 2004) and some other international efforts as well as the ICF system. The contributions made by experts in four meetings organised by the WPA-IPPP working group in 2006, 2007 and 2008 have been taken into consideration. This review stresses key studies on the impact of psychiatric illness in the overall functioning of individuals. Narrative review of studies providing detail of controversial aspects is discussed through out the article on the following key issues: 1) Conceptual framework and models of health functioning and functional disability; 2) The role of functional disability in psychiatric classification; 3) Disability in the international classification systems of mental disorders and its cultural adaptations; 4) The role of functional disability in person-centred approaches in psychiatry.

## 3. Health-related functional disability: conceptual framework and models

Two partially related but distinct models of disability coexist in Medicine; they provide divergent assessments of this construct in the mental health area. One is based on the 'Activities of Daily Living' (ADL) and it was originated in the US right after World War II to measure functioning in cancer patients and in physical rehabilitation (Karnofsky & Burchenal, 1949). The other is based on a broader concept of functional impairment. It originated at the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980, which gave forward to the current International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).

### 3.1 *The 'Activities of Daily Living' approach to disability (ADL)*

In the 1960s, Katz (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and

Lawton and Brody (1969) distinguished two major groups of ADL: “basic” activities related to self-care such as eating and grooming (BADL), and “instrumental” activities such as cooking and handling money (IADL). This approach was used to develop the Katz ADL index (Katz, 1983) and the Barthel index (Barthel & Mahoney, 1965), which is still a standard rating scale to measure disability in geriatrics and other medical disciplines as well as the standard comparator to assess the psychometrics of related instruments (Dijkstra, Tiesinga, Plantinga, Veltman, & Dassen, 2005). In spite of its inconsistencies, the distinction between BADL and IADL is still deeply grounded in the medical assessment of disability (i.e. Freedman, Martin, Schoeni, & Cornman, 2008). In physical conditions ADL and ICF models may produce convergent results; whilst significant differences appear in mental disorders. In severe mental illness, high social support may be needed even when there is hardly any impairment in “basic” ADL.

The concept of ‘dependency’ or ‘care dependency’ derived from the ADL model in the early 1990s and it has provided an international framework for evaluation and care to frail population across the lifespan. For example: Japan (Takei, Takahashi, & Nakatani, 2008); Mexico (Dorantes-Mendoza, Avila-Funes, Mejía-Arango, & Gutiérrez-Robledo, 2007), the US (Freedman *et al.*, 2008), or the European Union. In 1998, the European Council made a recommendation to European Union member states to develop care for dependent population (persons with severe disability and need of support from a third person) based on the ADL approach. However, this approach has shown problems for international comparability (European Commission, 2003) and for the development of eligibility criteria which include severe mental illness. It is important to note that the term “dependency” is not mentioned in ICF.

Furthermore, severe impairment of functioning and high need of support in psychiatric disorders may not be mediated by ADL, but directly caused by symptoms and behavioural problems (i.e. monitoring due to suicidal thoughts or non-adherence related to lack of insight).

### 3.2 *The WHO ‘Environmental’ approach to ‘functional disability’*

Experience derived from the 1980 WHO International Classification of Impairment, Disability and Handicap (ICIDH), shifted the relationship of health and functioning from the consequences of a disease or condition to the result of complex interactions among the individual, the environment and the disease or condition. The new International Classification of Functioning, Disabilities and Health (ICF) (WHO, 2001) was designed taking into consideration this biopsychosocial/integrative approach (Stucki & Cieza, 2004). This system comprises three main components: body functions and structures, activities and participation, and environmental factors.

The ‘environmental factors’ make up the physical, social and attitudinal environment in which people live and conduct their lives. They are external

to persons and can have a positive or negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the individual's body function or structure. These factors are organized in the classification to focus on two different levels:

- (a) Individual – in the immediate environment of the person, including settings such as home, workplace and school. Included at this level are the physical and material features of the environment that an individual comes face to face with, as well as direct contact with others such as family, acquaintances, peers and strangers.
- (b) Societal – formal and informal social structures, services and overarching approaches or systems in the community or society that have an impact on individuals (organizations and services related to the work environment, community activities, government agencies, communication and transportation services, and informal social networks).

The ICF contextual factor section includes a fourth component called 'personal factors' (WHO, 2001). It comprises individual characteristics such as age, sex, social class, life experiences, etc, which are not included in ICF. ICF argues that it has not classified them due to the large cultural variance associated with these factors.

As it is well known, the WHO definition of disability is based on the codification of deficits, limitation of activities and restriction of participation (WHO, 2001). A group of expert have developed an operational definition based on the ICF model. According to the MHADIE group (Measuring Health And Disability In Europe), "disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors" (Leonardi *et al.*, 2006).

Here disability is linked to global functioning while in the ADL model it was linked to impairment in a reduced set of activities of daily living. In ICF, "functioning" is defined as a generic term which includes body functions and structures, activities and participation. It indicates the positive aspects of the interaction between the individual (with a health condition) and its context factors (*personal* and *environmental* factors).

Although ICF is accepted internationally as a groundbreaking and comprehensive system, several criticisms have been posed. Critics refer mainly to 1) Overall usability of the system, 2) Distinction between activity and participation, 3) Distinction between capacity and performance, 4) Need of additional qualifiers (volition and self-efficacy).

#### *Overall usability / feasibility and related instruments*

The applicability of the ICF in routine clinical practice is also a major debating point among experts. A series of initiatives have been put forward to improve the usability of ICF. A version has been developed for children

and adolescents (ICF-CY). The Mini-ICF-P is a short observer rating instrument for the assessment of disabilities, especially with regard to occupational functioning. It provides a short assessment of the following dimensions (1) adherence to rules and regulations, (2) structuring of time and day, (3) flexibility, (4) competency, (5) endurance, (6) assertiveness, (7) contact with others, (8) public exposure, (9) intimacy, (10) non-work activities, (11) self maintenance, (12) mobility (Linden & Baron, 2005).

A ICF check-list and ICF Core sets are also available for an increasing number of diseases. Core sets are subgroups of ICF items selected to capture those aspects of functioning that are most likely to be affected by specific disorders. Within a given disorder, both Brief and Comprehensive Core Sets can be established to serve specific purposes. About a dozen chronic conditions, including depression (Cieza, Chatterji, Andersen, Cantista, Herceg, Melvin, 2004) and bipolar disorders (Vieta, Cieza, Stucki, Chatterji, Nieto, Sánchez-Moreno *et al.*, 2007), have been categorized using the principles of ICF. There are also efforts to develop a generic ICF core set. Its proponents argue that although the specific core sets are useful for describing particular conditions, the generic set will be valuable to compare across health conditions, serving as a common language based on the principle of etiologic neutrality (Cieza, Geyh, Chatterji, Kostanjsek, Ustün, & Stucki, 2006).

Others propose that addressing facilitators and barriers may help experts to guide priorities for interventions. Linking interventions to aspects of participation valued by the patient/client seem to make a very real difference in promoting engagement in processes like goals and goal setting (Siegert, McPherson, & Taylor, 2004).

#### *Distinction between activity and participation*

WHO declares that is difficult to distinguish activity from participation and uses the same “d” code for both. It says that these domains can be used either together or separate. This choice produces a critical taxonomic problem in any classification system, and it may reflect tension between experts in the field, and family and user organizations during the development process of the ICF.

#### *Distinction between capacity/performance*

WHO also admits that the capacity/performance distinction may be hard to formulate in practice. The on-going MHADIE study may provide useful information on this issue.

#### *Additional qualifiers to ICF*

Nonderfelt (2006) argues that the ICF manual includes too much in health and at the same time, some of its contents lie outside the proper domain of health. He proposes the incorporation of an “opportunity qualifier” and emphasises that when assessing the holistic health of a person in a par-

ticular situation, what should be determined is normally not the actual ‘performance’ of a specific action but the ‘ability’ to perform this action in the situation in question. In this case *will* is playing a role in the whole process.

Others proposed that *opportunity* ‘per se’ is not enough and that including other qualifiers from existing assessment tools could be beneficial for a more comprehensive evaluation. For example, the Quality of Life Profile (QLP) incorporates a number of qualifiers for each of its questions including *importance* and *satisfaction*, with a qualifier for each domain of *opportunity* and *control*. This adds a very valuable depth to understanding an individual’s health and function that would be missing if considering *opportunity* as the only qualifier (McPherson, 2006).

De Kleijn-Vrankrijker (2006) posits the need of a *will qualifier* and to find out how to apply it to the capacity and performance qualifiers. In some of the classes in ICF, the term “purposeful” is used which implies some will in the meaning of the force that is driving a person to do or not to do something.

#### 4. Disability in the classification systems of mental disorders

The relationship between the disorder per-se and its consequences remain unsolved in psychiatric nosology. Mental health is the only area of diagnosis in which disability/impairment are not just consequences of disease (coded as ICF) but a key diagnostic domain (coded in ICD-10). For example, Mental Retardation/Intellectual disability is a single entity or condition, which is classified at the same time in both systems (Salvador-Carulla & Bertelli, 2008). Functional impairment is not only regarded as a consequence of a disorder but also a key criterion for providing a standard diagnostic coding in depression. Therefore, disability and functioning are at the same time part of two separate and theoretically complementary classification systems: the diagnostic system and its consequences on functioning and activity. This overlapping of criteria in current classification systems has not been addressed properly.

##### 4.1 Role of functioning/disability in DSM

In DSM the classification of disorders is provided in Axis I and II, whilst their consequences are measured as a global activity index in Axis V. However, a major overlapping exists across both coding domains, as impairment of activity/functioning has been incorporated as a main diagnostic criterion in all major psychiatric disorders. For example, the ‘B’ criterion for schizophrenia states: “For a significant portion of time one or major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset”. This criterion implies an associa-



tion between axis I and axis V which is based on the Global Assessment of Functioning (GAF) (Goldman, Skodol, & Lave, 1992). Another example is the 'C' criterion for major depressive disorder: 'The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning'. This criterion shows that a decrease in GAF scores should be expected for patients with major depressive disorder. For axis II, a relation to GAF scores can be expected as well. The 'C' criterion for personality disorder in DSM-IV-TR (2) focuses on an 'enduring pattern' that 'leads to clinically significant distress or impairment in social, occupational, or other important areas of functioning' (Lehman, Alexopoulos, Goldman, Jeste, & Üstün, 2002; Tungstrom, Soderberg, & Armelius, 2005).

Axis V represents the GAF scale in which the clinicians judge patients' overall levels of functioning during a particular time. Functioning is considered a composite of three major areas: social functioning, occupational functioning, and psychological functioning. The GAF scale, based on a continuum mental health and mental illness, is a 100-point scale, 100 representing the highest level in all areas. Results of research in the areas of validity and clinical use of DSM components are some of the reasons for the local and international efforts to improve this system. The work on how and where to implement the necessary upgrades and corrections of this model in several of its structural aspects including the domains of disability and functioning began several years ago and has cumulated a significant literature including a special section in *Psychiatric Services* (Goldman, 2005). The combination of symptoms and functioning in the same scale makes the measuring of functional impairment itself inaccurate (Kupfer, First, & Regier, 2002). A separate assessment of functioning was suggested and the DSM-IV Social and Occupational Functioning Assessment Scale (SOFAS) was developed to overcome this problem although its overall reliability for functional assessment provided poor results in several studies (Roy-Byrne, Dagadakis, Unutzer, & Ries, 1996; Janca, 2001).

By requiring the presence of impairment before a psychiatric diagnosis can be made, the possibility of intervening early in the disease will be jeopardized. However, the dilemma is that given the limited resources and the need for equity regarding who gains access to services, the threshold for a specific condition to be considered a mental disorder should ultimately be determined by the level of dysfunction. An expanded assessment of functioning/activities has been suggested in DSM-V (First & Westen, 2007).

#### *4.2 Role of functioning/disability in ICD-10 (Mental and Behavioral Disorders)*

The weight of the functioning/disability domain in psychiatric diagnosis is lower in ICD-10 (WHO, 2007a) than in DSM, as it is mainly used for subclassification of disorders according to severity. For example, distinction between mild depressive episode (F32.0) and moderate depressive episode

(F32.1) depends on the 'difficulty in continuing with ordinary activities'. Recent international studies provide evidence that even when using minimum criteria set in ICD-10 to make a diagnosis of depressive episode, those who met the criteria had disability comparable to other chronic conditions. When depression is comorbid with physical illnesses it makes the disability significantly worse (Moussavi *et al.*, 2007).

The International Advisory Group for the Revision of ICD-10 Mental and Behavioural Disorders recommended against having functional impairment/ disability as part of the inclusion criteria for any specific disorder, as it is generally relatively non-specific with respect to diagnosis. The Advisory Group also suggested to provide definitions of functional impairment and disability that are consistent with the International Classification of Functioning, Disability and Health (ICF) and refer readers to the ICF for additional information on the classification of functional status. The Advisory Group recommended that any material deemed necessary about functional impairment and functional thresholds be included as part of the material generated for specific disorders or broader groups of disorders and that such material make use of the ICF framework. The group also recognized that the construct of disability is culturally embedded and it should be considered as a part of any formulation (WHO, 2007b).

To be used alongside ICD-10 classification of mental disorders, the evaluation of disability has been adapted from ICF in several ways. First, an axis on functional disability was included at the Multiaxial Presentation of the ICD-10 for use in adult psychiatry. This Axis II of ICD was conceptualized in accordance with the principles of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and it served to rate disabilities in relation to the tasks and roles expected from the individual in his/her socio-cultural setting. This axis covers specific areas of functioning clustered in four main categories: Personal Care, Occupation, Family and household, and Functioning in a broader Social Context. These four categories contain subcategories adding to 14 areas of functioning. Originally, these areas were measured using the WHO Short Disability Assessment Schedule which showed modest reliability results (Janca, Kastrup, Katschnig, López-Ibor, Mezzich, & Sartorius, 1996a; Janca, Kastrup, Katschnig, López-Ibor, Mezzich, & Sartorius 1996b; Janca Ahern, & Rock, 2001).

Second, a new and expanded version of the WHO Disability Assessment Schedule (WHODAS-II) was developed to assess disability in any medical condition, worldwide, including mental health disorders following the ICF approach (Kim *et al.*, 2005). MHADIE study is collecting data on disability across different conditions. When completed we may obtain a better understanding of the relationship of mental disorders and disability, and the differences in ADL domains between mental disorders and other medical diseases (Nieto-Moreno, Gimeno Blanco, Adan, Garcia-Olmos, Valle, Chatterji *et al.*, 2006).

Third, ICF core sets for psychiatric disorders are being developed. For example, the Brief ICF Core Set for depression included a total of 31 categories out from an initial set of 323; with 9 on body functions, 12 on activities and participation and 10 on environmental factors. A core set for bipolar disorders has also been developed (Vieta *et al.*, 2007).

#### 4.3 Cultural adaptations: Disability in IGDA, GLADP and CCMD

The International Guidelines for Diagnostic Assessment (IGDA) (IGDA Workgroup, 2003) and its Latin-American version: ‘Guía Latinoamericana de Diagnóstico Psiquiátrico’ (GLADP) (Berganza, Mezzich, & Jorge, 2002), both contain adaptations of the concepts established in Axis II of ICD-10. Section 6 of IGDA comprises items concerning functioning, social context, cultural framework and quality of life. These guidelines involve a new comprehensive diagnostic model that articulates a standardized multiaxial evaluation with a personalized idiographic one. The corresponding recommendations concerning the conceptualization and formulation of a comprehensive diagnostic statement are the matter of Sections 7 and 8. Section 7 focuses on the standardized multiaxial formulation, involving clinical disorders, disabilities, contextual factors, and, as a new axis, quality of life (Berganza *et al.*, 2002). During the last years this approach has been expanded to other areas of medicine and it has incorporated the construct functioning/disability as one of the main components of the “Person Centered Diagnosis” model (Saloum & Mezzich, 2010; Salvador-Carulla & Gasca, 2010).

GLADP contemplates in its axis II, areas and degree of disability in four different categories (personal care, occupational functioning, family functioning and social functioning in general). Disability can be a consequence of medical or mental illness, the affected areas and degrees are to be coded in this axis, while its causes are coded in axis I (APAL, 2004). This axis corresponds to axis II of ICD-10 and axis V of DSM-IV. Studies to measure the validity of IGDA are taking place in several countries of Latin America.

The Chinese Classification of Mental Disorders, 3<sup>rd</sup> revision (CCMD-3) is an ethnomedical classification grounded in symptomatology and etiology (Chen, 2002). It incorporates impairment of functioning in the diagnosis of several culture-bound disorders, following an approach closer to DSM than to ICD.

#### 4.4 The role of disability/functioning in person-centered approaches

##### *Classification of the American Association of Intellectual and Developmental Disabilities*

Within mental health, the field of Intellectual Disabilities has developed a long-standing experience in the use of the “positive appraisal” model. In 1992, the classification system developed by the American Association of Intellectual and Developmental Disabilities (AAIDD; formerly called

AAMR for 'Mental Retardation') released a classification system which provided specific dimension to assess the "adaptive behaviour" in Intellectual Disabilities -Dimension II: Adaptive behaviour (Conceptual, social and practical skills) - (AAMR, 2002). The 11<sup>th</sup> edition of the AAIDD classification follows the same model (AAIDD, 2010). It includes 3 domains, 16 types, and 26 skills. The AAIDD/AAMR classification also provides a system to evaluate the level or intensity of support needs and the planning process to implement these supports. Although this classification system implied a major conceptual advance, its usability and feasibility has been relatively low for routine practice and administration purposes.

#### *Institutional Program for Psychiatry for the Person (IPPP)*

The World Psychiatric Association (WPA) has developed the IPPP Program and a related Person-centred Integrative Diagnosis (PID). This WPA taskforce is working to provide a new framework to ascertain the role and the weight of disability and functioning in the psychiatric evaluation process (Mezzich, 2007). For the construction of PID the WPA group is paying close attention to the following key points: First, the informational domains to include, of course illnesses, but perhaps also disabilities, health related problems and positive aspects of health. Second, the descriptive tools to be employed, such as categorizations (classical and probabilistic), dimensions, and narratives. Third, the evaluators, including patients, clinicians, scientific experts, family, caregivers and pertinent community figures. Contributions to consider in the development of PID Functioning and Disability component come from many areas of intense growth: the "recovery movement", i.e. a model of care based on improving the coping and inner resources of the individual working together with other patients and other stakeholders (Anthony, 1993; Slade, 2009, 2010); the rehabilitation field; the integration of health and social services movement; and the flourishing of quality of life and protective factors as key elements in comprehensive diagnosis.

IPPP emphasizes the public health component of a psychiatry for the person. A number of papers have provided evidence of the relationship between disability and use of resources. Therefore, disability and functioning are relevant to set up case-mix and other groups of patients relevant to health planning (Boot *et al.*, 1997, Ruggeri *et al.*, 2000). Compared to people with a physical disability, those with a mental disability require a different set of services to allow them to participate in the community and conduct their activities of daily living (Williams *et al.*, 2001). Again, the role of disability in case-mix development shows peculiarities in mental health that are not seen in other medical conditions.

The IPPP model also underlines the value of positive functioning and resilience in the assessment of mental health. Concepts such as adaptive functioning and adaptive behaviour, autonomy, capacity, skills, abilities should be revised and adapted to mental health.

## 5. Discussion

### *Functional disability and related concepts*

The concept of health is dynamic, complex and closely linked to functioning. Many environmental and personal factors influence health and functioning. To date there has been very little debate on the differences between the ADL and the ICF approaches to health-related functioning and disability; given their consequences in the assessment and care of severe mental illnesses. Even more surprising is the little interest shown by psychiatry in the operational conceptualisation of psychiatric disability and its implications for psychiatric diagnosis.

Health-related disabilities may be conceptualised by two different systems: ADL disability (based on ADL approach) and functional or contextual disability (based on the WHO approach). Functional disability may be further divided into 'environmental disability' and 'personal disability', although only functional environmental disability is classified and coded at the ICF.

The conceptual background of the WHO-ICF approach has a broader perspective and it allows a better description of the functional impairment related to mental disorders. Following the logic of WHO terminology, 'health-related environmental functioning' may be defined as the capacity of an individual to live independently in the community with little or no help from others (high autonomy); while health-related disability may be defined as a persistent impairment of environmental functioning.

To date, no classification has been provided of functional or contextual personal disability. Three provisional categories or dimensions have been suggested in this area: Scene-setting personal factors, potentially modifiable personal factors and social relationships (Badley, 2006).

The concept of 'dependency' or 'care dependency' is based on the ADL model, and it is not mentioned in the ICF. Tentatively a definition of dependency may be derived from the WHO concept of Autonomy at the Ottawa Charter and the related glossary of terms (WHO, 1998). Within this context 'functional environmental dependency' may be regarded as a meta-construct related to the interaction between disability, needs and support, and their implications in designing care planning and management. This definition is important to rehabilitation professionals and planners who address and resolve the instances in which people with disabilities are being prevented from engaging in a major area of life as the result of external barriers, ineffective services and supports. (Scherer, Mc Anney, & Sax, 2006).

Contrary to the rest of medical conditions, severe disability with high special needs (dependency) may not be mediated by ADL in many mental illnesses. Hence, the medical models of disability, which are based on ADL, may not fit the particularities of mental health. However, the validity of the ADL model in comparison to ICF should be explored further as some ex-

amples of the usability of the ADL approach to the assessment of dependency in psychiatric disorders have been provided (Takei *et al.*, 2008).

Three main concerns on the usability and content validity of the ICF approach relate to its feasibility, the ability/capacity distinction and the volition domain.

1. The development of new assessment tools such as the WHODAS-II, the ICF core sets and, in the future, a generic ICF set, are major steps towards improving the feasibility of ICF in routine practice.

2. The delineation between ability and capacity needs further development. Being able to do something not always result in action, patients may have the capacity but fail to perform.

3. ICF includes “lack of will” as a personal factor to cover the above type of situation. In other instances, if the patient has the capacity but external factors such as discriminatory practices prevent the performance, then, ICF includes “environmental factor” to cover for this type of situation.

The domain volition has created important debate. Philosophical theories, psychological approaches and social ideologies have taken a deep and often controversial look into the terms *volition*, *will power*, *free will* or just *will*. Even the approach of philosophers such as Nietzsche or Schopenhauer, just to name a couple, have been interpreted in multiple different ways. In the realms of our countries and current social global disparities, we continue to question how free is this *will*?, how much is determined by outside factors, like social constrains, moral rules, community expectations, and the law? Furthermore, to what extend the unconscious mind plays a role in the final step of will, that is its ‘action?’ Therefore, the simplistic approach to will and the attempts to standardize possible outcomes or behaviours has to be looked out very carefully and on a personal-environmental symbiotic manner if we want a more real and perhaps useful model.

A key factor in the process of health promotion and prevention of health conditions is *health behaviour change* and providers play a major role in it. When we talk of opportunity qualifiers, as if just *will* is the main aspect of the individual not to perform, we can inadvertently place burden and blame on the patient. Health behaviour change, as explained by some experts, takes place in stages: contemplation, intention to change, planning and action (Prochaska & Di Clemente, 1983). A major variable in this process is *health-related self-efficacy*, a variable that is not included in ICF. Clearly, health care providers can play a major role by tailoring their interventions to the level of the individual’s readiness for change in health and functioning. In this way patients feel supported and not blamed. Based on the above lines by Nieuwenhuijsen (2006), he proposes a *readiness for change qualifier*, which applies not only to the patients but also to their family members, health care providers, policy makers, employers, co-workers, etc.

*Functional disability and psychiatric diagnosis*

The standardization of proper diagnosis of disability in psychiatry is further complicated by intrinsic factors of mental conditions such as: stigmatization, sub threshold psychiatric symptoms, medication side effect, and psychological trauma. The authors believe that the person-centred approach, which tailors specific needs and goals of the individual in a multidiscipline context and involves family, social networks and resources, represents a step forward in the assessment of disability in psychiatry. The idiographic component of IPPP, including its narrative section, could prove very helpful in this effort. Manuals, guides, and classification systems may be cornerstone to the process of quality care, but they might not be the panacea for every patient or clinical setting.

Given the mounting literature comparing ICD-10 and DSM-IV classification systems, it is surprising the lack of comments on the different approaches to the functional disability domain provided by the two systems. The vast involvement of functioning in the diagnosis of psychiatric disorders in DSM may reflect construct validity problems in this classification system, both in the diagnostic axes (I and II) and in the functioning axis (V). Apart from overlapping with clinical symptoms, axis V does not provide an adequate assessment of function/activity consequences of psychiatric disorders (Roy-Byrne *et al.*, 1996; Kupfer *et al.*, 2002); and the assessment of functioning in this classification system should be completely changed (Lehman *et al.*, 2002; First *et al.*, 2007).

ICD-10 is not affected to the same extend than DSM by the overlapping of symptoms and consequences of disorders. However examples of use of activity/functioning as a key classifier of mental disorders and 'vice versa' have been provided (i.e. mild versus moderate depression). The development of a complementary classification system of environmental functioning within the WHO family of classifications and its related taxonomy is a major improvement and it has significant implications in the holistic classification of mental disorders. Curiously enough, this fact has not been highlighted when analysing the usability of ICD-10 in psychiatry (Janca *et al.*, 2001, First *et al.*, 2007). A series of related tools such as the Mini-ICF-P (Linden *et al.*, 2005) and the ICF core sets for severe mental disorders such as bipolar disorders (Vieta *et al.*, 2007), may improve the assessment of disability and functioning in this population group. An ICF core set for severe mental disorders in general may also be needed in the near future.

The concepts of functioning, contextual disability and functional disability could be additionally framed as complex adaptive systems, based on the Complexity Theory. This model has been previously used to conceptualise healthcare (McDaniel & Driebe, 2001), nursing (Chaffee & McNeill, 2007) or psychiatric symptoms (Sel, 1997).

## 6. Conclusion

Disability is very relevant for classification and grouping in health management and planning using case-mix. The experience gained using the adaptive functioning approach in other areas such as Intellectual disabilities may help the application of that model in psychiatric diagnosis. From a conceptual perspective, the WHO family of classifications (ICD-10/ICF) provides a more advanced assessment of disability and functioning than DSM.

Within the philosophy of IPPP, the patient's input is of utmost need for the design of the comprehensive diagnostic model. However, disability has not been fully included in the classification system. How to properly frame, measure and interpret data related to functioning and disability may be a fundamental challenge to a successful IPPP development. The group on disability and functioning of PID understands the challenges posed by the current trends and needs in psychiatric diagnosis and more specifically in the areas of functioning and disability. Nevertheless, with harmonious cooperation from our colleagues and all pertinent clinical sources we look forward to contribute to the development of the best possible model of psychiatric diagnosis by taking into consideration the perspectives of patients, family and society in order to enhance clinical care and health promotion. The person-centred approach promoted by WPA may provide a significant contribution to the operational definition of 'Personal Functioning'.

## Acknowledgements

*We acknowledge the World Psychiatric Association (WPA) in its Institutional Program for Psychiatry for the Person (IPPP) working group. Particularly we thank other experts who contribute to the disability working subgroup: Professors M. Linden, A. Soghoyan and R. Williams, as well as Prof. J. E. Mezzich, for his comments.*

## References

Alptekin, K., Erkoc, S., Gogus, A. K., Kultur, S., Mete, L., Ucock, A., & Yazici, K.M. (2005). Disability in schizophrenia: clinical correlates and prediction over 1-year follow-up. *Psychiatry Research*, *15*, 135 (2), 103-111.

American Association on Intellectual and Developmental Disabilities (2010). *Intellectual Disability: Definition, Classification, and Systems of Support*. 11th ed. Washington, DC: American Association on Intellectual and Developmental Disabilities



American Association on Mental Retardation (2002). *Mental Retardation: Definition, classification and systems of support*. 10<sup>th</sup> ed. Washington DC: American Association on Mental Retardation

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders. DSM-IV-TR*. Washington: American Association on Mental Retardation

Anthony, W. (1993). Recovery form mental illness. The guiding vision of the mental health services systems in the 1990's. *Journal of Psychosocial Rehabilitation*, 16, 11-23.

APAL (2004). Guia Latinoamericana de Diagnostico Psiquiatrico *Latin American Guide of Psychiatric Diagnosis* (GLAPD). México: Editorial de la Universidad de Guadalajara.

Badley, E. M. (2006). *More than facilitators and barriers: Fitting the full range of environmental and personal contextual factors into the ICF Model*. 12<sup>th</sup> Annual North American Collaborating Center Conference on ICF. Vancouver, British Columbia, Canada.

Berganza C. E., Mezzich J. E., & Jorge, M. R. (2002). Latin American Guide for Psychiatric Diagnosis (GLDP). *Psychopathology*, 35 (2-3), 185-90.

Boot, B., Hall, W., & Andrews, G. (1997). Disability, outcome and case-mix in acute psychiatric in-patient units. *British Journal of Psychiatry*, 171, 242-246.

Chaffee, M.W., McNeill, M. M. (2007). A model of nursing as a complex adaptive system. *Nursing Outlook*, 55 (5), 232-241.

Chen, Y. F. (2002). Chinese classification of mental disorders (CCMD-3): towards integration in international classification. *Psychopathology*, 35 (2-3), 171-175.

Cieza, A., Chatterji, S., Andersen, C., Cantista, P., Herceg, M., Melvin, J., Stucki, G., de Bie, R. (2004). ICF Core Sets for depression. *Journal of Disability Rehabilitation Medicine*, (44 Suppl.), 128-134.

Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., Ustün, B. T., & Stucki, G. (2006). Identification of candidate categories of the International Classification of Functioning Disability and Health (ICF) for a Generic ICF Core Set based on regression modelling. *BMC Medicine Research Methodologic*, 27, 6-36.

de Kleijn Vrankrijker, M. W. (2006). On health, ability and activity: comments on some basic notions in the ICF. Response on some issues raised by Nordenfelt. *Disability Rehabilitation*, 15, 28 (23), 1475-1476.

Dijkstra, A., Tiesinga, L. J., Plantinga, L., Veltman, G., & Dassen, T. W. N. (2005). Diagnostic accuracy of the Care Dependency Scale. *Journal of Advanced Nursing*, 50 (4), 410-416.

- Dorantes-Mendoza, G., Avila-Funes, J. A., Mejía-Arango, S., Gutiérrez-Robledo L. M. (2007). Factors associated with functional dependence in older adults: a secondary analysis of the National Study on Health and Aging, Mexico, 2001. *Review Panama Saluda Public*, 22 (1), 1-11.
- European Commission (2003). *Feasibility Study –Comparable Statistics in the Area of Care of Dependent Adults in the European Union*. Luxembourg: Office for Official Publications of the European Communities.
- First, M. B., & Westen, D. (2007). Classification for clinical practice: how to make ICD and DSM better able to serve clinicians. *International Review of Psychiatry*, 19 (5), 473-481.
- Freedman, V. A., Martin, L. G., Schoeni, R. F., & Cornman, J. C. (2008). Declines in late-life disability: The role of early- and mid-life factors. *Social Science & Medicine*, 66 (7), 1588-1602
- Goldman, H. H., Skodol, A. E., Lave, T. R. (1992). Revising axis V for DSM-IV: a review of measures of social functioning. *American Journal of Psychiatry*, 149 (9), 1148-1156.
- Goldman, H. H. (2005). Special Section on the GAF: Editor's Introduction: "Do You Walk to School, or Do You Carry Your Lunch?". *Psychiatric Services*, 56, 419.
- Janca, A. (2001). Reliability of DSM-IV Axis V Scales. *American Journal of Psychiatry*, 158, 1935-1936.
- Janca, A., Ahern, K., & Rock, D. (2001). Introducing ICD-10 into psychiatric coding practice: a WA experience. *Journal Public Health*, 25 (4), 376-377.
- Janca, A., Kastrup, M., Katschnig, H., Lopez-Ibor, J. J. Jr., Mezzich, J. E., & Sartorius, N. (1996b). The World Health Organization Short Disability Assessment Schedule (WHO DAS-S): a tool for the assessment of difficulties in selected areas of functioning of patients with mental disorders. *Sociology Psychiatry Epidemiology*, 31, 349-354.
- Janca, A., Kastrup, M., Katschnig, H., López-Ibor, J. J. Jr., Mezzich, J. E., & Sartorius, N. (1996a). Contextual aspects of mental disorders: a proposal for axis III of the ICD-10 multiaxial system. *Acta Psychiatrica Scandinavica*, 94 (1), 31-6.
- Karnofsky, D. A., & Burchenal, J. H. (1949). *The clinical evaluation of Chemotherapeutic agents. En: Evaluation of chemotherapeutic agents*. New York: Columbia University Press.
- Katz, S. (1983). Assessing self maintenance: activities of daily living, mobility and instrumental activities of daily living. *Journal of the American Geriatrics Society*, 31, 721-727.
- Katz, S., Ford, A., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. The Index of ADL: A standardized measure of biological and psychosocial function. *JAMA*, 185 (12), 914-919.

- Kim, J. M., Stewart, R., Glozier, N., Prince, M., Kim, S. W., Yang, S. J., Shin, I. S., & Yoon, J. S. (2005). Physical health, depression and cognitive function as correlates of disability in an older Korean population. *International Journal of Geriatric Psychiatry*, 20 (2), 160-167.
- Kupfer, D. J., First, M. B., & Regier, D. A. (2002). Research Agenda for DSM V. Chapter 5, Washington, D.C.: *American Psychiatric Publishing, Inc.*
- Lawton, M. P., & Brody, E. M. (1969). The functional assessment in rehabilitation of elderly people: Self maintaining and Instrumental Activities of Daily Living. *Gerontologist*, 9, 179-186.
- Lehman, A. F., Alexopoulos, G. S., Goldman, H., Jeste, D., & Üstün. B. (2002). Mental Disorders and Disability: Time to Reevaluate the Relationship?. In Kupfer DJ, First MB, Regier DA (Eds.). A Research Agenda for DSM-V (pp. 201-218). Washington, DC: *American Psychiatric Association*.
- Leonardi, M., Bickenbach, J., Ustun, T. B., Kostanjsek, N., & Chatterji, S. (2006). MHADIE Consortium. The definition of disability: what is in a name? *Lancet*, 7 (368), 1219-1221.
- Linden, M., & Baron, S. (2005). The “Mini-ICF-Rating for Mental Disorders (Mini-ICF-P)”. A short instrument for the assessment of disabilities in mental disorders [Article in German]. *Rehabilitation*, 44 (3), 144-1451.
- Mahoney, F. I. & Barthel, D. W. (1965). Functional Evaluation: The Barthel Index. Maryland State. *Journal of Medicine*, 14, 61-65.
- Mathers, C. D., & Loncar, D. (2006). Projections of global mortality and burden of disease from 2002 to 2030. *PLoS Medicine*, 3 (11), 442.
- Mayo, N. E., Nadeau, L., Levesque, L., Miller, S., Poissant, L., & Tamblyn, R. (2005). Does the addition of functional status indicators to case-mix adjustment indices improve prediction of hospitalization, institutionalization, and death in the elderly? *Medical Care*, 43 (12), 1194-1202.
- McDaniel, Jr., R. R., & Driebe, D. J. (2001). Complexity science and health care management. *Advances in Health Care Management*, 2, 11-36.
- McPherson, K. (2006). What are the boundaries of health and functioning- and who should say what they are? *Disability Rehabilitation*, 28 (23), 1473-1474
- Mezzich, J. E. (2007). Psychiatry for the Person: articulating medicine’s science and humanism. *World Psychiatry*, 6 (2), 1-3.
- Mezzich, J. E., Berganza, C. E., Von Cranach, M., Jorge, M. R., Kastrup, M. C., Murthy, R. C., Okasha, A., Pull C., Sartorius, N., Skodol, A. E., Zaudig, M. (2002). *Essentials of the WPA international guidelines for diagnostic assessment (IGDA) world psychiatric association workgroup on IGDA*. New York: World Psychiatric Association.

- Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V., Ustun, B. (2007) Depression, chronic diseases, and decrements in health: results from the Health World Surveys. *The Lancet*, 370, 851-858.
- Nieto-Moreno, M., Gimeno Blanco, P., Adan, J., Garcia-Olmos, L., Valle, J., Chatterji, S., Leonardi, M., & Ayuso-Mateos, J., Grupo de Investigacion ITACM. (2006). Applicability of the ICF in measuring functioning and disability in unipolar depression in Primary Care settings. *Actas Españolas de Psiquiatría*, 34 (6), 393-396.
- Nieuwenhuijsen, R. (2006). On health, ability and activity: Comments on some basic notions in the ICF commentary. *Disability Rehabilitation*, 28 (23), 1477-1479.
- Nordenfelt, L. (2006). On health, ability and activity: Comments on some basic notion in the ICF. *Disability Rehabilitation*, 28 (23), 1461-1465.
- Prince, M., Patel, V., Saxena, S., Maj, M., Maselko, Phillips, M. R., & Rahman, A. (2007). No health without mental health. *The Lancet*, 8, 370(9590), 859-877.
- Prochaska, J. O., & Di Clemente, C. C. (1983). Stages and Processes of Self-Change of Smoking: Toward an Integrative Model of Change. *Journal of Consulting and Clinical Psychology*, 51 (3), 390-395
- Roy-Byrne, P., Dagadakis, C., Unutzer, J., & Ries, R. (1996). Evidence for limited validity of the revised global assessment of functioning scale. *Psychiatry Service*, 47 (8), 864-866.
- Ruggeri, M., Leese, M., Thornicroft, G., Bisoffi, G., & Tansella, M. (2000). Definition and prevalence of severe and persistent mental illness. *The British Journal of Psychiatry*, 177, 149-155
- Salloum, I. M., & Mezzich J. E. (2010). Person-centered diagnosis. *International Journal of Integrated Care*, 29, 10, suppl. e027.
- Salvador-Carulla, L., & Bertelli, M. (2008). 'Mental retardation' or 'intellectual disability': time for a conceptual change. *Psychopathology*, 41 (1), 10-16.
- Salvador-Carulla, L., & Gasca, V. I. (2010). Defining disability, functioning, autonomy and dependency in person-centered medicine and integrated care. *International Journal of Integrated Care*, 29,10, suppl. e025.
- Sanderson, K., & Andrews, G. (2002). Prevalence and severity of mental health-related disability and relationship to diagnosis. *Psychiatry Service*, 53 (1), 80-86.
- Scherer, M., Mc Anney, D., & Sax, C. (2006). Opportunity is possibility; performance is action: measuring participation. *Disability Rehabilitation*, 28 (23), 1467-1471.
- Sel, R. (1997). Dissociation as complex adaptation. *Medical Hypotheses*, 48 (3), 205-208.

- Siegert, R., McPherson, K., & Taylor, W. (2004). Toward a cognitive affective model of goal setting in rehabilitation. Is self regulation theory a key step? *Disability Rehabilitation*, 26 (20), 1175-1183.
- Slade, M. (2009). *Personal Recovery and Mental Illness: A Guide for Mental Health Professionals*. Cambridge: Cambridge University Press.
- Slade, M. (2010). Mental illness and well-being: the central importance of positive psychology and recovery approaches. *BMC Health Services Research*, 26, 10-26.
- Stucki, C., & Cieza, A. (2004). The International Classification of Functioning, Disability and Health (ICF) Core Sets for rheumatoid arthritis: a way to specify functioning. *Annals of Rheumatic Diseases*, 63 (suppl. II) ii40.
- Takei, T., Takahashi, H., & Nakatani, H. (2008). Developing a uniformed assessment tool to evaluate care service needs for disabled persons. *Japan Health Policy*, 86, 373-380
- Tungstrom, S., Soderberg, P., & Armelius, B.A (2005). Relationship between the Global Assessment of Functioning and other DSM axes in routine clinical work. *Psychiatry Service*, 56 (4), 439-443.
- Vieta, E., Cieza, A., Stucki, G., Chatterji, S., Nieto, M., Sánchez-Moreno, J., Jaeger, J., Grunze, H., & Ayuso-Mateos, J. L. (2007). Developing core sets for persons with bipolar disorder based on the International Classification of Functioning, Disability and Health. *Bipolar Disorder*, 9 (1-2), 16-24.
- Williams, R. F. G., & Doessel, D. P. (2001). *Economics and Mental Health Care: Industry, Government and Community Issues*. Ashgate: Aldershot.
- World Health Organization (1980). *International Classification of Impairments, Disabilities, and Handicaps. A Manual of classification relating to the consequences of disease*. Geneva: WHO.
- World Health Organisation (1998). *Health Promotion Glossary*. Geneva: WHO.
- World Health Organization (1999). *The World Health Organization Disability Assessment Schedule Phase II Field Trial Instrument*. Geneva: WHO.
- World Health Organisation (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO.
- World Health Organisation (2007a). *International Classification of Diseases, 10th edition. (ICD Version 2007)*. Geneva: retrieved at <http://www.who.int/classifications/apps/icd/icd10online/>
- World Health Organisation (2007b). 1st Meeting of the International Advisory Group for the Revision of ICD-10, *Mental and Behavioural Disorders*, 11 - 12 January 2007 - Geneva, Switzerland.



Inclusive school placements and surplus/deficit  
in performance for students with intellectual disabilities:  
Is there a connection?\*

Nancy L. Waldron<sup>1</sup> & James McLeskey<sup>2</sup>

Abstract

*Vianello and Lanfranchi (2009) have presented a noteworthy hypothesis regarding students with intellectual disabilities, when they suggest that the location of a student's education can produce a surplus (or deficit) relative to academic and social/behavior development. We provide a brief review of research on the effectiveness of placement settings for students with intellectual disabilities conducted in the U.S. that provides some support for the surplus/deficit hypothesis. This is followed by a review of the qualities of inclusive programs that may produce a surplus for these students, and how schools with these qualities are developed. Finally, we discuss the need to support schools as they transform practices to make differences ordinary for students with disabilities.*

Keywords: Intellectual Disabilities; Inclusion; Program Effectiveness; School Change

\* Received: 13 March 2010, Revised: 07 May 2010, Accepted: 07 May 2010.

\* This article is a reply to the debate invited by Vianello & Lanfranchi (this Journal, issue 1/2009).

<sup>1</sup> School of Special Education, School Psychology, & Early Childhood Studies PO Box 117050, University of Florida, Gainesville, FL 32611. E-mail: waldron@coe.ufl.edu

<sup>2</sup> School of Special Education, School Psychology, & Early Childhood Studies. E-mail: mcleskey@coe.ufl.edu

## 1. The surplus/deficit hypothesis and students with intellectual disabilities: Does setting add value?

Vianello and Lanfranchi (2009) present a very noteworthy hypothesis related to the education of students with intellectual disabilities, as they ask whether the location of a student's education can produce a surplus (or deficit) in academic and social development. They begin to develop theoretical support for this hypothesis by reviewing research that demonstrates many students with intellectual disabilities seem to have a deficit in academic and social development relative to their presumed cognitive ability.

For example, research by Zigler and Bennet-Gates (1999) suggests that students with intellectual disabilities are often characterized by "more negative behavior in the presence of strangers, psychological dependence on adult figures personally-known to subjects, less expectation of success, more importance given to external motivation rather than internal" (Vianello & Lanfranchi, 2009, p. 43). These behaviors often result in less motivation to work, lower self-esteem, and less self-efficacy, which leads the individual to a deficit with respect to presumed intellectual ability.

Vianello and Lanfranchi then suggest that while many students with intellectual disabilities exhibit this deficit, some seem to exhibit a surplus, or academic achievement and social development that is greater than what would be expected based on their presumed cognitive ability. They then hypothesize that the student's environment, whether poor, typical, or enriched, may influence the extent to which a student is either in deficit or surplus.

Research presented by Vianello and Lanfranchi, while very much preliminary, provides suggestive evidence that students with intellectual disabilities and one of four syndromes (Down syndrome, Fragile X syndrome, Cornelia de Lange syndrome, and Prader-Willi syndrome) may be more likely to exhibit a surplus when they are educated in an inclusive setting. The authors conclude that the surplus/deficit hypothesis remains to be confirmed, and that the research they have reviewed regarding this hypothesis has generated more questions than answers.

We concur with this perspective, and believe that the deficit/surplus hypothesis related to students with intellectual disabilities is very provocative and worthy of study. This concept seems to be similar to the 'value added' approach to assessment that is increasingly used in schools in the U.S. (Sanders & Horn, 1998; Sanders, 2006). This approach is built upon the idea that educators can predict the amount of academic progress a student will make in a given year by determining gains the student made in previous years. Thus, a student is expected to make an average gain each year, and interventions may be evaluated based on the extent to which they exceed these expected gains or add value to the student's education. The question that Vianello and Lanfranchi asked, when placed within a value added context,



then becomes “Does an education in an inclusive setting add value to the education of students with intellectual disabilities?”

A major interest of ours related to this topic concerns the qualities of inclusive settings that may result in adding value to the education of students with disabilities. In a later section of this paper, we will address this issue, but first we review research from the U.S. that seems to support the surplus/deficit hypothesis, indicating that an education in an inclusive setting may add value to the education of many students with intellectual disabilities and produce a surplus for many students with intellectual disabilities.

## 2. What does evidence on the efficacy of placement settings from the U.S. say about the surplus/deficit hypothesis?

Most of the research that has been conducted regarding the effectiveness of placement settings for students with intellectual disabilities in the U.S. has revealed that these students do not benefit from full-time, separate class placements, and at times segregated placements can have negative effects on social development and academic achievement or produce a deficit (Dunn, 1968; Carlberg & Kavale, 1980; Madden & Slavin, 1983; Epps & Tindal, 1988; Freeman & Alkin 2000; Salend & Duhaney, 2007). In contrast, inclusive placements tend to produce outcomes that are at least as great, and sometimes significantly greater than separate class placements.

For example, in a review of the impact of placement setting on the academic and social attainment of students with intellectual disabilities, Freeman and Alkin (2000) found several benefits for inclusive placements. Regarding social outcomes, these authors found that students in inclusive placements tended to have better developed social skills and competence. In addition, while students with intellectual disabilities were not as well accepted as their general education peers, their level of acceptance tended to be positively correlated to the time they spent in the general education classroom. Freeman and Alkin found that low levels of social acceptance could be addressed, to some extent, through intensive training programs for teachers and peers.

Freeman and Alkin (2000) also examined research that addressed academic outcomes for students with intellectual disabilities in inclusive settings, and found that outcomes were also positively correlated with the time spent in an inclusive classroom. They note that while academic outcomes tended to be greater for students with mild intellectual disabilities, academic outcomes for students with severe intellectual disabilities were at least as great, and sometimes greater than outcomes for peers who were educated in separate settings.

A review by Salend and Duhaney (2007) reached similar conclusions. These authors found that students with severe disabilities who were educa-

ted in inclusive classrooms experienced greater increases in skills learned, engaged and instructional time, and exposure to academic content than peers who were educated in separate settings. With regard to social and behavioral development, students who were included often had more friendships, increased social interactions with classmates, greater social acceptance than students educated in separate settings, better self-concepts, and fewer disruptive behaviors.

Although most research is supportive of inclusive placements for students with intellectual disabilities, Epps and Tindal (1988) concluded that some research favors separate classes over inclusive placements for some students. Others have concurred with this conclusion, as they have noted some variability in outcomes regarding the effectiveness of placement settings for students with disabilities (Carlberg & Kavale, 1980; Freeman & Alkin 2000). These differences are likely related to the quality of the inclusive or separate class settings (Leinhardt & Pallay, 1982; Epps & Tindal, 1988; Fox & Ysseldyke, 1997; Salend & Waldron & McLeskey, 1998; Duhaney, 1999; McLeskey & Waldron, 2000, 2002, 2006). For example, Fox and Ysseldyke found that when an inclusive program was poorly designed and teachers were provided little support or professional development, few supports were provided in general education classrooms to meet the needs of students with disabilities and student outcomes were not enhanced.

In sum, these findings provide some support for the surplus/deficit hypothesis. Most of the research conducted to this point reveals that students with intellectual disabilities seem to make more academic and social progress when placed in well-designed, inclusive classrooms. However, if these programs are not well designed, negative outcomes may result (Madden & Slavin, 1983; Fox & Ysseldyke, 1997; McLeskey & Waldron 2006). These findings suggest that critical variables that influence student outcomes are the quality of the program that is delivered, and the extent to which the general education setting is changed to better accommodate the needs of students with disabilities (Salend & Duhaney, 1999; Waldron & McLeskey, 1998). In the next section, we provide a brief review of research related to the quality of effective, inclusive programs.

### 3. What are the qualities of well-designed inclusive programs that result in a “surplus” or value-added for students with disabilities?

Although many have speculated regarding the qualities of effective, inclusive schools based on their work in these settings (e.g., Burstein, Sears, Wilcoxon, Cabello, & Spagna, 2004; Salend & Duhaney, 2007; McLeskey, Rosenberg, & Westling, 2010), surprisingly little systematic research has been conducted that addresses this important issue. This area of research has begun to be addressed by Dyson, Farrell, Polat, Hutcheson, and Gallan-

naugh (2004) and Farrell, Dyson, Polat, Hutcheson, & Gallannaugh, (2007) by identifying schools in the U.K. that are both inclusive (i.e., a relatively large number of students with disabilities are educated in the school), and effective (i.e., the school produces greater than expected academic gains for students with disabilities). While the definition of effective schools based on academic achievement is narrow (i.e., academic measures used may not accurately reflect the progress of all students, especially those with more substantial disabilities, and social development is not considered), and the definition of inclusivity is relatively gross (i.e., number of students with disabilities educated in a given school), this research represents a good beginning in examining the qualities of effective, inclusive schools.

Dyson *et al.* (2004) and Farrell *et al.* (2007) addressed this topic by identifying twelve schools in the U.K. that had high levels of school inclusivity, as well as high levels of student achievement. Case studies were conducted in each of these schools, and produced five primary findings.

(1) There was not a single model for inclusion, as schools developed inclusive programs in many different ways. However, these effective, inclusive schools shared several principal elements, including:

- Services provided for students with disabilities were characterized by flexibility. This included flexible instruction in the general education classroom, as well as flexible support to meet changing student needs. Customizing support was dependent on careful assessment, planning, and monitoring of student progress.
- Teaching assistants were used to break down rigid grouping patterns, as they provided in-class support, and individual or small group instruction.
- Most schools had sophisticated systems for monitoring student progress, and used this data to carefully plan individual student support and interventions.
- High performing schools used strategies directed toward raising the achievement of all students in the school, as well as specific strategies to address the needs of students who struggled to learn.

(2) Schools had an ethos that was positive and welcoming of all students, and a strong commitment to the principle of inclusion or equity for all students. This included a clear recognition of the practical challenges that were presented by inclusion, as well as the need to use limited resources very effectively and efficiently. Alongside this commitment to equity, the effective, inclusive schools also had a strong commitment to excellence, which included improving achievement and holding high expectations for all students.

(3) Instructional practices in general education classrooms were readily identifiable by observers as 'good' practice, and were seen as likely to be effective. Furthermore, these practices were flexible, and were changed as necessary by teachers to meet particular student needs.

(4) Multiple strategies were used to increase student achievement. This included raising the overall quality of teaching in the school; focusing directly on raising student achievement to predetermined targets; and focusing on any identified weaknesses in underlying skills and seeking to remedy these weaknesses.

(5) Educators typically viewed the education of students with disabilities as a normal part of their responsibilities, simply as a fact of life. However, teachers had significant challenges addressing the behavior of students who were disruptive, and viewed the behavior of these students as the most significant difficulty they faced in raising student achievement.

It is noteworthy that, as part of this research, Dyson *et al.* (2004) also used a national database to examine the relationship between level of school inclusivity and student achievement. This analysis resulted in a slightly negative, but significant correlation between inclusivity and achievement. Based on this finding, the authors concluded that it was not the inclusivity of a school that improves achievement, but specific practices (as previously described) that occurred within these settings that improved achievement. The relevance of this finding to the surplus/deficit hypothesis is unclear for two reasons. First, this data primarily relates to the achievement of students with milder disabilities, and may not relate to inclusion when examining outcomes for students with intellectual disabilities. Second, the outcomes measured do not include important outcome measures for students with intellectual disabilities that could be improved by placement in inclusive classrooms (e.g., social development, friendships, academic skills not included as part of national standards and achievement measures).

While the research of Dyson and colleagues (2004) suggests that the quality of inclusive programs is a critical consideration when examining the effectiveness of these settings, further research is needed to determine which qualities of these settings result in improved outcomes or a surplus for students with severe disabilities. It seems likely that many of the qualities of inclusive schools described by Dyson and colleagues (2004) could be relevant for programs that include students with severe disabilities, and these qualities should provide a good starting point for research that addresses this issue.

#### 4. How are effective, inclusive schools developed?

Several of the reviews of research on inclusion that were cited previously noted that developing an inclusive school is not a simple task, and these programs are, at times, poorly developed (Madden & Slavin, 1983; Epps & Tindal, 1988; Salend & Duhaney, 1999). The qualities of effective, inclusive programs that were previously described are good qualities for

any school, and will surely be recognized as such by many teachers and other professionals. This information can be used to help those who seek to develop an inclusive program, as information is provided regarding critical areas to address in program planning and implementation. However, as Farrell *et al.* (2007) and others (McLeskey & Waldron, 2000, 2006) have noted, there is not a model for effective, inclusive practices. Thus, the qualities that characterize these programs are only useful for general guidance, and the particulars of any inclusive program must be tailored to the specific characteristics and needs of a local school (McLeskey & Waldron, 2006).

But of course, simply recognizing the qualities of effective, inclusive programs is not sufficient, as much research on school change has demonstrated that good ideas such as these do not travel of their own volition and become implemented in schools (Fullan, 2007). Systematic school change activities are required to achieve the changes that are needed to develop effective, inclusive programs (McLeskey & Waldron, 2000, 2002). Research suggests that to develop an effective, inclusive school, the following are critical considerations in ensuring the success of the school change.

- A. *A team of teachers and other stakeholders should spend several months planning the changes* that will occur as the inclusive program is developed (McLeskey & Waldron, 2000, 2006). This allows teachers and other stakeholders the opportunity to engage in discussions and understand the rationale for inclusion, and build a commitment for inclusion. In addition, this group should work collaboratively to determine school needs, develop goals, generate a plan for change, and work to implement this plan. One frequent outcome of this group is the development of a learning community within the school, as teachers and other stakeholders work together to solve problems as they arise and support one another through the difficult change process (Waldron & McLeskey, 2010).
- B. *Adequate resources must be provided* to support teachers in meeting student needs, and these resources must be used efficiently and effectively. These resources include adequate numbers of teachers and other professionals, as well as support for adequate planning time, curricular resources, technology needs, student grouping arrangements that ensure high quality instruction, and other critical needs.
- C. *Teachers and other professionals should be provided with high quality professional development* to learn the knowledge and skills needed to meet student needs. This high quality professional development should focus on teacher identified skills, and should be long-term, job-embedded, and supported by in-class coaching (Pugach, Blanton, Correa, McLeskey, & Langley, 2009).
- D. *The principal, teachers, and other stakeholders should work to distribute leadership to support school improvement activities* (Waldron & McLeskey, 2010). Research evidence indicates that successful school

change is supported as leaders are developed beyond the school principal, and responsibilities for providing leadership for different aspects of school improvement are distributed among the school staff (Waldron & McLeskey, 2010). The act of distributing leadership is an important step toward changing the culture of the school, and moving in a direction where stakeholders work collaboratively to engage in joint problem solving, data sharing and analysis, and shared decision-making.

## 5. Supporting inclusion, transforming schools, and making differences ordinary

Vianello and Lanfranchi note in their review of studies related to the surplus/deficit hypothesis in Italian schools, that they did not have a population of students to study who were educated in separate schools, as almost all students with intellectual disabilities in Italy are educated in inclusive schools. Unfortunately, inclusion of students with intellectual disabilities is not a matter of social policy in most other countries. For example, in the U.S. research has revealed that in 2007-08, only about 17% of students with intellectual disabilities spent most of the school day in general education classrooms, while about 78% of these students were educated on a regular school campus but were segregated for much or all of the school day from their general education peers, and 6% were educated in separate schools (McLeskey, Landers, Williamson, & Hoppey, 2010).

Interestingly, in some states in the U.S., inclusion of students with intellectual disabilities is much more prevalent (Smith, 2007). For example, one state includes over 60% of students with intellectual disabilities in general education classrooms for most of the school day, while five additional states similarly include at least 25% of these students (Smith, 2007). Thus, inclusion of large numbers of students with intellectual disabilities can be accomplished in the U.S., given current policies and funding for education, but most states have chosen not to engage in major policy initiatives to ensure that this occurs.

It is noteworthy that this large scale segregation of students with intellectual disabilities continues in the U.S., in spite of the fact that researchers have long questioned the value of separate class placements for these students (e.g., Dunn, 1968), and federal legislation provides a clear preference for inclusive placements for these and other students with disabilities (Williamson, McLeskey, Hoppey, & Rentz, 2006). For example, in 1968 Dunn reviewed research related to the effectiveness of separate class placements, and concluded that these settings resulted in poor educational outcomes for students with intellectual disabilities (or produced a deficit). He went on to characterize the widespread practice of segregating students with intellectual disabilities from their general education peers for much or all of

the school day as “morally and educationally wrong” (p. 5), and “obsolete and unjustifiable from the point of view of the pupils so placed” (p. 6). In response to these shortcomings, Dunn recommended that students with intellectual disabilities be educated in general education classrooms for much of the school day.

Our experience suggests that the development of inclusive programs for large numbers of students with disabilities is highly dependent upon the development of an ethos of support for inclusion by school and community leaders. Unless this support is developed and carefully cultivated, inclusive programs are difficult to support or sustain. In essence, this ethos results in the acceptance of persons with disabilities as a natural part of the school community. This acceptance then leads to the assumption that they will be active participants in the school community in much the same way as other community members are participants, and provides the moral purpose for transforming schools in ways that make many student differences ordinary (Artiles, Harris-Murri, & Rostenberg, 2006; McLeskey & Waldron, 2007).

To illustrate, we have found that well designed inclusive schools seek to make differences ordinary in general education classrooms (McLeskey & Waldron, 2000, 2007). Of course, in any classroom, there is a range of academic and social behavior that is considered typical, ordinary, and acceptable to the teacher (McLeskey & Waldron, 2007). In effective, inclusive classrooms that share an ethos in support of inclusion, teachers arrange curriculum and instruction so that they can accommodate a broad range of differences among their students. This allows a broader range of students to naturally fit into the classroom.

Teachers create more accommodating classrooms by planning curriculum and instruction to ‘fit’ a broad range of students, and also by providing supports to students in the classroom. Well-designed inclusive programs ensure that these supports are natural and unobtrusive whenever possible. This is important not only to ensure that students are a natural part of the classroom, but also because research evidence indicates that supports that fit the ebb and flow of the classroom are preferred by teachers and are more likely to continue to be used over time (Gersten, Chard, & Baker, 2000; Klingner, Arguelles, Hughes, & Vaughn, 2001). More specifically, this research suggests that supports that are accepted and used by teachers should:

- Fit into the ongoing details of daily classrooms instruction;
- Be perceived by teachers as effective for students with disabilities as well as other students in the classroom; and
- Enhance and build on the teacher’s current repertoire of instructional practices.

Thus, supports that are used in an inclusive classroom should be the least intrusive and most natural supports that are effective (McLeskey & Waldron, 2007). This type of support helps to ensure that students with disabili-

ties are perceived as fully accepted, active participants in the classroom (McLeskey, Rosenberg, & Westling, 2010), and that supports are sustained over time by teachers (McLeskey & Waldron, 2007). This is not to suggest that students with disabilities do not need 'special' support in an inclusive classroom, but it does suggest that what counts as special needs not always stand out in inclusive settings (Pugach, 1995).

Another critical consideration in keeping differences ordinary in inclusive schools is ensuring that the 'rhythm of the day' for students with disabilities is as much like the school day of other students as possible (McLeskey & Waldron, 2007). For example, students should only be removed from the general education classroom when another placement produces improved academic or behavioral outcomes that cannot be achieved in the general education classroom. This is not to say that separate classes should never be used; to the contrary, these classes can be used to improve the development of important skills for students with disabilities. However, keeping the use of such programs to a minimum is important because these classes can result in (McLeskey & Waldron, 2007):

- Disruption of the student's routine and the routine of the general education classroom;
- Reduction of instructional time because of transitions from one setting to another;
- Fragmentation of the student's schedule, which makes it difficult for the teacher to provide effective, coherent instruction that meets the student's needs;
- Difficulty for the student who must learn the rules of several different classroom settings;
- Stigma for the student, who may be viewed as different by others, which may result in difficulty making friends in the general education classroom.

A final critical consideration related to making differences ordinary in inclusive classrooms is ensuring that students with disabilities are part of the academic and social community of the classroom and school. Ferguson (1995) observed in inclusive classrooms and noted that this participation in the community of the classrooms did not always occur, as some students with disabilities seemed to be 'in' the classroom, but not 'of' the classroom. She noted that this seemed to occur because many teacher assumptions regarding students with disabilities remained unchallenged and unchanged. These assumptions included:

- Students with disabilities continued to be viewed as 'irregular', even though they were included;
- Students with disabilities needed specialized support that could not be provided by the classroom teachers;
- Specialized support was provided only by the special education teacher.



Closely examining these assumptions is a critical part of developing effective, inclusive programs where students with disabilities are active participants in the academic and social communities of classrooms and schools. More specifically, inclusion is not about moving special education into the general education classroom. It is about making differences ordinary in these settings, and ensuring that students with disabilities are fully accepted members of the classroom and school community. “An underlying assumption of successful inclusive programs is that all children will be included in the learning and social communities of the school and that classrooms in these schools will be so accepting of diversity that no one will be left out from the very beginning” (McLeskey & Waldron, 2007, p. 166).

## 6. Conclusion-Developing inclusive programs that produce a surplus, and that further a social justice agenda

Dyson (1999) suggests that the justification for inclusion has been built upon two distinct discourses. One of these discourses addresses the effectiveness of inclusive programs, while the other addresses the rights of students and social justice. The research agenda that is suggested by Vianello and Lanfranchi is obviously important to the effectiveness discourse, and has the potential to add significantly to the extant research that provides support for high quality inclusive programs that improve academic and social outcomes and produce a surplus for students with disabilities (Madden & Slavin, 1983; Freeman & Alkin, 2000; Salend & Duhaney, 2007). Indeed, this work could provide further support regarding the efficacy of inclusive programs for improving outcomes (and ultimately improving the lives) of students with intellectual disabilities.

Inextricably coupled with the effectiveness discourse is the social justice and rights discourse regarding the inclusion of students with intellectual disabilities (Dyson, 1999; Artiles *et al.*, 2006). This discourse has obviously occurred in Italy, as most persons with intellectual disabilities are included in the schools and community as a natural part of everyday activities. Unfortunately, this discourse has not occurred in many other countries, and is necessary to provide the support and moral purpose that results in the motivation for transforming schools and making students with intellectual disabilities a natural part of these settings (Artiles *et al.*, 2006; McLeskey & Waldron, 2006, 2007). We are optimistic that the current emphasis in many countries on accountability for outcomes for all students has the potential to move this discourse along, and could provide many settings in which to further explore how and why inclusive programs seem to add surplus to the lives of students with intellectual disabilities.

## References

- Artiles, A., Harris-Murri, N., & Rostenberg, D. (2006). Inclusion as social justice: Critical notes on discourses, assumptions, and the road ahead. *Theory into Practice, 45* (3), 260-268.
- Burstein, N., Sears, S., Wilcoxon, A., Cabello, B., & Spagna, M. (2004). Moving toward inclusive practices. *Remedial and Special Education, 25*, 104-116.
- Carlberg, C., & Kavale, K. (1980). The efficacy of special versus regular class placement for exceptional children: A meta-analysis. *The Journal of Special Education, 14*, 295-309.
- Dunn, L. (1968). Special education for the mildly retarded: Is much of it justifiable? *Exceptional Children, 35*, 5-22.
- Dyson, A. (1999). Inclusion and inclusions: Theories and discourses in inclusive education. In H. Daniels & P. Garner (Eds.). *World yearbook of education 1999: Inclusive education* (pp. 36-53). London: Kogan Page.
- Dyson, A., Farrell, P., Polat, F., Hutcheson, G., & Gallannaugh, F. (2004). *Inclusion and pupil achievement. Research Report RR578*. University of Newcastle: Newcastle Upon Tyne, UK.
- Epps, S., & Tindal, G. (1988). The effectiveness of differential programming in serving students with mild handicaps: Placement options and instructional programming. In M. C. Wang, M. C. Reynolds, & H. J. Walberg (Eds.). *Handbook of special education: Research and Practice, Volume I* (pp. 213-248). New York: Pergamon Press.
- Farrell, P., Dyson, A., Polat, F., Hutcheson, G., & Gallannaugh, F. (2007). Inclusion and achievement in mainstream schools. *European Journal of Special Needs Education, 22* (2), 131-145.
- Ferguson, D. (1995). The real challenge of inclusion. *Phi Delta Kappan, 77* (4), 281-287.
- Fox, N., & Ysseldyke, J. (1997). Implementing inclusion at the middle school level: Lessons from a negative example. *Exceptional Children, 64* (1), 81-98.
- Freeman, S., & Alkin, M. (2000). Academic and social attainments of children with mental retardation in general education and special education settings. *Remedial and Special Education, 21*(1), 3-18.
- Fullan, M. (2007). *The new meaning of educational change. (4th ed.)*. New York: Teachers College Press.
- Gersten, R., Chard, D., & Baker, S. (2000). Factors enhancing sustained use of research-based instructional practices. *Journal of Learning Disabilities, 33*, 445-457.

- Klingner, J., Arguelles, M., Hughes, M., & Vaughn, S. (2001). Examining the school-wide "spread" of research-based practices. *Learning Disability Quarterly, 24*, 221-234.
- Leinhardt, G., & Pally, A. (1982). Restrictive educational settings: Exile or haven? *Review of Educational Research, 52* (4), 557-578.
- Madden, N., & Slavin, R. (1983). Mainstreaming students with mild handicaps: Academic and social outcomes. *Review of Educational Research, 53* (4), 519-569.
- McLeskey, J., Landers, E., Williamson, P., & Hoppey, D. (2010). *The least restrictive environment mandate of IDEA: Are we moving toward educating students with disabilities in less restrictive settings*. Unpublished manuscript. Gainesville, FL: University of Florida.
- McLeskey, J., Rosenberg, M., & Westling, D. (2010). *Inclusion: Effective practices for all students*. Upper Saddle River, NJ: Prentice Hall.
- McLeskey, J., & Waldron, N. (2000). *Inclusive schools in action: Making differences ordinary*. Alexandria, VA: ASCD.
- McLeskey, J., & Waldron, N. (2002). School change and inclusive schools: Lessons learned from practice. *Phi Delta Kappan, 84*(1), September, 65-72.
- McLeskey, J., & Waldron, N. (2006). Comprehensive school reform and inclusive schools: Improving schools for all students. *Theory into Practice, 45* (3), 269-278.
- McLeskey, J., & Waldron, N. (2007). Making differences ordinary in inclusive classrooms. *Intervention in School and Clinic, 42* (3), 162-168.
- Pugach, M. (1995). On the failure of imagination in inclusive schooling. *The Journal of Special Education, 29*, 212-223.
- Pugach, M., Blanton, V., Correa, V., McLeskey, J., & Langley, L. (2009). *The role of collaboration in supporting the induction and retention of new special education teachers*. (Technical paper, National Center to Improve Policy and Practice in Personnel Preparation (NCIPP)). Gainesville, FL: University of Florida.
- Salend, S., & Duhaney, L. (2007). Inclusion: Yesterday, today, and tomorrow. In J. McLeskey (Ed.). *Reflections on Inclusion: Classic articles that shaped our thinking* (pp. 125-159). Arlington, VA: CEC.
- Salend, S., & Duhaney, L. (1999). The impact of inclusion on students with and without disabilities and their educators. *Remedial and Special Education, 20* (2), 114-126.
- Sanders, W. (2006). *Comparisons among various educational assessment value-added models*. Paper presented at the Power of Two-National Value-Added Conference, Columbus, OH. Retrieved on February 8, 2010 from [http://www.talentteachers.com/pubs/comparisons\\_models\\_sanders.pdf](http://www.talentteachers.com/pubs/comparisons_models_sanders.pdf).

Sanders, W., & Horn, S. (1998). Research findings from the Tennessee Value-Added Assessment System (TVAAS) database: Implications for educational evaluation and research. *Journal of Personnel Evaluation in Education, 12* (3), 247-256.

Smith, P. (2007). Have we made any progress? Including students with intellectual disabilities in regular education classrooms. *Intellectual and Developmental Disabilities, 45* (5), 297-309.

Vianello, R., & Lanfranchi, S. (2009). Genetic syndromes causing mental retardation: Deficit surplus in school performance and social adaptability compared to cognitive capacity. *Life Span and Disability, 12* (1), 41-52.

Waldron, N., & McLeskey, J. (2010). Establishing a collaborative culture through Comprehensive School Reform. *Journal of Educational and Psychological Consultation, 20* (1), 58-74.

Waldron, N., & McLeskey, J. (1998). The impact of a full-time Inclusive School Program (ISP) on the academic achievement of students with mild and severe learning disabilities. *Exceptional Children, 64* (2), 395-405.

Williamson, P., McLeskey, J., Hoppey, D., & Rentz, T. (2006). Educating students with mental retardation in general education classrooms: An analysis on national and state trends. *Exceptional Children, 72* (3), 347-361.

Zigler, E., & Bennett-Gates, D. (1999). *Personality development in individuals with mental retardation*. Cambridge, UK: Cambridge University Press.

## Evaluative Study on the social validity of the developmental disability parent training program Stepping Stones Triple P

Paul Probst,<sup>1</sup> Iain Glen,<sup>2</sup> Julia Spreitz<sup>3</sup> & Florian Jung<sup>4</sup>

### Abstract

*There is a worldwide lack of scientifically proven and commonly accessible preventative intervention programs for families with disabled children. The aim of the present study is to evaluate ethical and practicability aspects of the social validity of the Australian developmental disability parent training program Stepping Stones Triple P (SSTP), which has not been previously tested in Europe. The SSTP parent video was rated by a sample of 33 German master-level students of psychology, using quantitative and qualitative questionnaires. Overall, the ethical acceptability of the program was evaluated as moderately positive and the practical applicability as neutral, that is neither positive nor negative. Ethical acceptability was rated as positive for all the parental strategies demonstrated in SSTP except for Planned Ignoring, which was rated as neutral, and Quiet Time and Time Out, both of which were rated as moderately negative. Overall program flexibility for parents and children was rated as moderately negative. Critical comments focused on the overuse of traditional operant conditioning techniques and the lack of contemporary more developmentally orientated behaviour methods. Though findings support the assumption of a moderately positive social validity overall, the analysis revealed clear limitations. Thus, some revision of the program is suggested. Further research should expand to various groups having everyday experience with children with disabilities as well as to various diagnostic categories.*

**Keywords:** Parent training, Developmental disability, Stepping Stones / Triple P, Social validity, Time out, Ethical aspects

\* Received: 20 October 2009, Revised: 17 February 2010, Accepted: 22 March 2010.

<sup>1</sup> Dept. of Psychology, University of Hamburg, Germany, email: probst@uni-hamburg.de

<sup>2</sup> Dept. of Psychology, University of Hamburg, Germany, email: iainglen@gmx.de

<sup>3</sup> Dept. of Psychology, University of Hamburg, Germany, email: jspreitz@web.de

<sup>4</sup> Dept. of Psychology, University of Hamburg, Germany, email: florian.jung@uni-hamburg.de

## 1. Introduction

Epidemiological studies have shown that the prevalence of challenging behavioural symptoms, such as self-injury, aggression, noncompliance, overactivity, and ritualistic behaviours in children with severe intellectual disabilities and related developmental disabilities (Batshaw, 1994) ranges between 40% and 65% (Roberts, Mazzucchelli, Studman, & Sanders, 2006). As a result, the parents of developmentally disabled children are faced with high care-giving demands in their everyday life, which frequently result in heightened stress and lead to impairment in their individual as well as family adjustment (Plant & Sanders, 2007a). Family-orientated preventative and rehabilitative approaches have been increasingly developed in recent years in order to provide professional support for parents in these high-risk situations (cf. Tonge, Brereton, Kiomall, Mackinnon, King, & Rinehart, 2006). A central type of preventive family intervention is the cognitive-behavioural parent training, which is carried out either with single parents, in parent groups or with a combination of both. Key goals of this approach are (1) the facilitation of adequate parental health cognitions, such as the acquisition of strong self-efficacy beliefs and the provision of a scientifically based disability concept comprising appropriate social cognitions on the causes, nature, and consequences of the disability and its associated behavioural symptoms; (2) the enhancement of parenting strategies and skills in order to promote the child's cognitive and emotional development and manage behaviour problems (Mah & Johnston, 2008).

### *1.1 Structure and goals of the SSTP program*

The parent training program Stepping Stones Triple P (SSTP; Triple P: "Positive Parenting Program") is targeted towards the broad diagnostic group of children with developmental disabilities (Batshaw, 1994), who are at particular risk of developing behavioural or emotional problems (Sanders, Mazzucchelli, & Studman, 2004a; Sanders, Turner & Markie-Dadds, 2004b). The SSTP program (Sanders, Mazzucchelli, & Studman, 2003b) is a modification of the general parenting program Standard Triple P (Wiese, Stancliffe, & Hemsley, 2005; Heinrichs, Hahlweg, & Doepfner, 2006; Thomas & Zimmer-Gembeck, 2007; Nowak & Heinrichs, 2008; Sanders, 2008; Sanders, Ralph, Sofronoff, Gardiner, Thompson, & Dwyer, 2008;). While the SSTP program has already been tested in Australia (Queensland), (Roberts *et al.*, 2006; Plant & Sanders, 2007b; Whittingham, Sofronoff, & Sheffield, 2006; Whittingham, Sofronoff, Sheffield, & Sanders, 2009a, b, c) it is only beginning to be tested in North-America and Europe (Probst, 2009).

The program material includes (a) "Stepping stones: A survival guide for families with a child who has a disability" DVD and booklet (Sanders, Mazzucchelli, & Studman, 2003a, b); (b) "SSTP family workbook" (Sanders,

Mazzucchelli, & Studman, 2003c) (adapted for German-speaking people: Sanders *et al.*, 2004b; Sanders, Mazzucchelli, & Studman, 2005). The SSTP program is targeted at parents of children with disabilities aged between 2 and 12 years and has five levels of intervention strength to meet the individual family's support needs (Sanders *et al.*, 2004a). Level 1 consists of basic information about SSTP available on the Internet and through other mass media. Level 2 involves the provision of information and advice for a specific parenting concern and level 3 includes active skills training. Level 4 involves broad focus parenting skills training with a combination of group and individual sessions, while level 5 is an enhanced behavioural family intervention program for families where parenting difficulties are complicated by additional family distress. Levels 4 and 5 have already been evaluated in Australia (Roberts *et al.*, 2006; Plant & Sanders, 2007b; Whittingham, Sofronoff, Sheffield, & Sanders, 2009a, b, c).

Preliminary evidence, based on three controlled studies from Australia with 177 families with a developmentally disabled child (in total 103 intervention group families, 74 control group families) supports the assumption that SSTP is effective with regard to child problem and parent behaviour (Probst, 2009; Whittingham *et al.*, 2009a).

According to the program authors (Sanders *et al.*, 2004a), the SSTP program aims to promote positive caring relationships between parents and their children and to help parents develop effective management strategies. Specific aims are to (1) increase parents' competence in managing common behaviour problems and developmental issues found among children with disabilities; (2) reduce parents' use of coercive and punitive methods of disciplining children; (3) improve parents' personal coping skills and reduce parenting stress; (4) improve parents' communication about parenting issues and help parents support one another in their parenting roles; and (5) develop parents' independent problem-solving skills (Sanders *et al.*, 2004a). Key aspects of positive parenting comprise "ensuring a safe and interesting environment", "creating a positive learning environment", "using assertive discipline", "adapting to having a child with a disability", "having realistic expectations", "being part of the community", and "taking care of yourself as a parent" (Sanders *et al.*, 2003b).

### *1.2 Aims of the present study*

As there is a lack of preventative, evidence-based (Chambless & Hollon, 1998) and easily (commonly) accessible family intervention programs for developmental disabilities worldwide (Reichow, Volkmar, & Cicchetti, 2008) (cf. Loesel, 2006) testing the Stepping Stones Triple P Program is a matter of some scientific and social urgency also in German-speaking and other European countries. Until now studies on its effectiveness and social validity have been carried out exclusively by the Sanders research group in Australia (Probst, 2009). Studies on social validity are urgently required for

ensuring program quality (Rossi, Lipsey, & Freeman, 2004) because cross-cultural and cross-countries transferability of parent training programs cannot be presupposed. The social validity of an intervention method is assessed to the extent its goals, treatment methods and treatment effects are accepted by relevant social groups currently involved in the interventions or in the future (see Callahan, Henson, & Cowan, 2008). These groups are defined as (1) professionals, such as therapists or special education teachers, (2) paraprofessionals, such as non-licensed educational aides, higher-level students of psychology, medicine, and education, parents trained as co-therapist; (4) nonprofessionals, such as lay parents and other significant lay persons in the community.

The aim of the present study is to evaluate key aspects of the social validity of the SSTP program. Guided by the work of Whittingham, Sofronoff and Sheffield (2006) the following two dimensions of the social validity of the SSTP parent training program will be investigated in the target group: (1) “ethical acceptability” and (2) “practical applicability”.

The ethical acceptability of an intervention method can be regarded as a key criterion of social validity because it only makes sense to evaluate a method’s applicability if the method is ethically acceptable with regard to common as well as professional ethical norms, such as the United Nations Convention on the Rights of the Child (Office of the United Nations High Commissioner for Human Rights, 2002) and the APA Ethical Principles of Psychologists and Code of Conduct (American Psychological Association, 2002). In addition to ethical acceptability, an intervention can only be considered as socially valid if it is perceived to be practically applicable for the target group, in this case the belief that goals and methods can be implemented by the parents of children with developmental disabilities.

The evaluation of the social validity of the program is based on the evaluation of the SSTP program described and demonstrated in the video “Stepping Stones: A Survival Guide for Families with a Child Who Has a Disability” (Sanders *et al.*, 2003a). The social validity of (a) global characteristics of the program, and (b) the specific parenting strategies contained in the program are investigated. The study is carried out in a group of master-level psychologists who are classified as paraprofessionals. Paraprofessionals often play key roles in the implementation and monitoring of preventive and rehabilitative family interventions (Oneal, Reeb, Korte, & Butter, 2006).

## 2. Method

### 2.1 Participants

A total of 45 master-level students of psychology took part voluntarily and anonymously in the study (85% female, mean age = 31.06 years, SD = 7.69). Based on the master studies curriculum, all students had attained the



bachelor level of psychology qualification as well as sound knowledge in clinical and educational psychology, intervention methods and professional ethics. The study was carried out in two sessions, which lasted 90 minutes each, with an interval of one week within a regular curriculum-based lecture given by the first author at the University of Hamburg, Germany. 33 participants took part in both sessions and filled out both parts of the quantitative questionnaire on the social validity of the SSTP (see section 2.2.2). This constituted the *core sample* on which the quantitative results of the study are based (Table 1 and 2). 79% were female and the mean age was 31.3 years ( $SD = 8.4$ ). The mean total number of semesters studied in psychology was 6.2 ( $SD = 2.1$ ). There was thus a drop out rate of 27%. There were no significant differences between the final sample and the dropouts with regard to demographic as well as evaluative variables.

The students filled out both parts of the qualitative questionnaire at home (see Table 3, items 1-6 belong to part 1, items 7-15 to part 2). The return rate was 73 percent, that is 24 of the core sample of 33 students completed both parts. Thus, there was a drop out rate of 27%. Again, there were no significant differences between the final sample of 24 students on which the results of the qualitative questionnaire are based (Table 3) and the dropouts with regard to demographic and evaluative variables.

## 2.2 Materials

### 2.2.1 Stepping Stones Video

The video shown is entitled “Stepping Stones Triple P: A survival guide for families with a child who has a disability” (total length: 80 min., Sanders *et al.*, 2005). It contains five parts with explanations of parenting situations. The headings of the five parts are as follows: Part One: “What is Positive Parenting? Seven key aspects of positive parenting”; Part Two: “Causes of behaviour problems”; Part Three: “Promoting children’s development: fourteen parenting strategies for developing a positive parent-child relationship, encouraging desirable behaviour and teaching new skills and behaviours”; Part Four: “Managing misbehaviour: eleven strategies”; Part Five: “Family survival tips: 5 recommendations for coping with everyday life”.

In each of the five parts the content is first introduced, followed by demonstrations of the relevant parenting situation. These took place at home between parents and their disabled child and are explained by Matthew Sanders in the form of an interview. Finally, the content is summarized. The video was dubbed into German in the version used in this study.

### 2.2.2 Quantitative questionnaire on the social validity of the SSTP

The quantitative questionnaire on the social validity of the SSTP contains a total of 43 items: (a) 38 items relate to different parts of the Stepping Stones program shown in the video and evaluate key aspects, strategies and

tips for positive parenting (items 1-37) as well as a program overall (item 38). They include 7 items on Key Aspects of Positive Parenting (part 1), 14 items on Strategies for Promoting Children's Development (part 3), 11 items on Strategies for Managing Misbehaviour (part 4), 5 items on Family Survival Tips (part 5), as well as one global evaluation item (see Table 1). The conception of the items was based on the study of Whittingham *et al.* (2006). The specific aspects of the strategies presented in the video were evaluated with regard to "ethical acceptability" and "perceived practical applicability" on a 5-point Likert scales (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree). Example items: (1) Establishing ground rules: "I consider the presented strategy to be ethically acceptable" (1 = "strongly disagree" to 5 = "strongly agree"); "I consider the strategy to be usable" (1 = "strongly disagree" to 5 = "strongly agree"); (2) Overall Evaluation: "I consider the parent training program SSTP to be ethically acceptable" (1 = "strongly disagree" to 5 = "strongly agree"); "I consider the parent training program SSTP to be usable" (1 = "strongly disagree" to 5 = "strongly agree").

(b) The questionnaire contained 5 additional items on global characteristics of the SSTP program. These were evaluated on a single dimension on the same 5-point scale. All five items are shown in Table 2. Example item: "The presented parenting behaviour leaves parents and children enough room for flexibility" (1 = "strongly disagree" to 5 = "strongly agree").

### 2.2.3 Qualitative questionnaire on the social validity of the SSTP

The qualitative questionnaire on the social validity of the SSTP contained 15 items with an open answer format (see Table 3). Items 1, 3, 4, 7, 8 and 12 related to parts 1 to 5 of the Stepping Stones video. Example item: "Please evaluate the presented key aspects of positive parenting demonstrated in part 1 and give reasons for your answer". Items 2, 5, 6, 8-11 included student statements from a previous pilot questionnaire pre-study on the SSTP with another sample of master-level psychology students from the University of Hamburg. Example item: "Please comment on the following statement on the video from a former student who evaluated this video: 'Quiet Time and Time Out are good for bringing peace to both parents and children'". Items 13-15 related to global characteristics of the program quality. Example item: "How would you characterize the recommended parenting behaviours". The answers to these items were categorised using a 5 point rating scale (1 = very negative, 2 = negative, 3 = neutral, 4 = positive, 5 = very positive) by two raters independently. The concordance between the raters was satisfactory ( $\kappa = 0.85$ ).

### 2.3 Procedure

The study was carried out in two sessions, each about 90 min long. In the first session, following an approximately 10 min introduction to the study and

the Stepping Stones Triple P parenting program (origin, target group, basic principles and structure), the students were shown the first three parts of the Stepping Stones Video using a video projector presentation. At the second session a week later the last two parts of the video were presented. The students were also briefly informed about the family workbook (Sanders *et al.*, 2003b, 2004b). The workbook focuses on the strategies presented in the video, the transfer of the strategies to everyday life and planning for high-risk situations (“planned activity training”, Sanders *et al.*, 2003c, pp. 125-149).

#### 2.4 Data Analysis

The statistical analysis of the data from the quantitative questionnaire was carried out using SPSS, Version 15. Where the distribution of the evaluations is reported the 5-point Likert scales are reclassified as follows: 1 = very negative, 2 = negative, 3 = neutral, 4 = positive, 5 = very positive.

### 3. Results

The results of the present study are based on the analysis of the quantitative questionnaire, the qualitative questionnaire, and the correlations between both instruments.

#### 3.1 Results from the quantitative questionnaire on the social validity of the SSTP

The results for the individual key aspects, parenting strategies and family survival tips presented in the Stepping Stones Video (Items 1-37) as well as the overall program evaluation (Item 38) are shown in Table 1 (pages 50-51).

The following results for the individual key aspects, parenting strategies and family survival tips presented in the Stepping Stones Video (Items 1-37) can be shown.

*Aspects of Positive Parenting.* The ethical acceptability of the principles presented in Part 1 of the video was rated by the participants on average as positive for all items. The means for the 7 individual aspects ranged between 4.06 and 4.75. The least positively evaluated aspect was “Using assertive disciplines” with  $M = 4.06$ . Similarly, practical applicability was predominantly rated positively, but to a lesser extent (means ranged between 2.97 and 3.55).

*Strategies for Promoting Children’s Development.* The ethical acceptability of the 14 Strategies for Promoting Children’s Development presented in Part 3 of the video was rated on average as positive for all items (means ranged between 3.33 and 4.85). Practical applicability was also evaluated predominately positively, though to a lesser extent (means ranged between 3.22 and 4.48).

Table 1 - *Results of the evaluation of key aspects and strategies in the SSTP and the overall program evaluation*

Item No.	Key aspects, Strategies and Tips for Positive Parenting	Ethical acceptability	Practical applicability
		M (SD)	M (SD)
<b>7 Key Aspects of Positive Parenting</b>			
1	(1) Ensuring a safe and interesting environment	4.42 (0.81)	3.55 (0.99)
2	(2) Creating a positive learning environment	4.65 (0.61)	3.35 (0.88)
3	(3) Using assertive discipline	4.06 (1.01)	3.09 (0.82)
4	(4) Adapting to having a child with a disability	4.60 (0.67)	3.50 (0.98)
5	(5) Having realistic expectations	4.63 (0.66)	3.44 (1.11)
6	(6) Being part of the community	4.72 (0.58)	3.47 (0.95)
7	(7) Taking care of yourself as a parent	4.75 (0.57)	2.97 (0.90)
<b>14 Strategies for Promoting Children's Development</b>			
8	(1) Spend quality time with your child	4.66 (0.70)	3.72 (0.89)
9	(2) Communicate with your child	4.73 (0.67)	3.97 (0.95)
10	(3) Show affection	4.85 (0.36)	4.48 (0.71)
11	(4) Praise your child	4.44 (0.88)	4.00 (1.05)
12	(5) Give your child attention	4.61 (0.70)	3.82 (0.73)
13	(6) Provide other rewards	3.91 (1.10)	3.79 (0.99)
14	(7) Provide engaging activities	4.65 (0.55)	3.56 (0.84)
15	(8) Set up activity schedules	4.24 (0.97)	3.56 (0.91)
16	(9) Set a good example	4.72 (0.52)	4.03 (0.86)
17	(10) Use physical guidance	4.12 (0.86)	3.52 (0.83)
18	(11) Use incidental teaching	4.55 (0.67)	3.97 (0.88)
19	(12) Use ask, say, do	4.27 (0.91)	3.67 (0.99)
20	(13) Teach backwards	4.09 (0.89)	3.22 (1.10)
21	(14) Use behaviour charts	3.33 (1.14)	3.39 (1.14)
<b>11 Strategies for Managing Misbehaviour</b>			
22	(1) Use diversion to another activity	3.70 (1.19)	2.94 (0.93)
23	(2) Establish clear ground rules	3.94 (1.00)	3.52 (1.00)
24	(3) Use directed discussion for rule breaking	3.97 (1.03)	3.72 (0.92)
25	(4) Use planned ignoring for minor problem behaviour	3.00 (1.16)	3.24 (1.00)
26	(5) Give clear, calm instructions	4.39 (0.79)	3.50 (0.76)
27	(6) Teach your child to communicate what he/she wants	4.18 (0.95)	2.88 (0.99)

Item No.	Key aspects, Strategies and Tips for Positive Parenting	Ethical acceptability	Practical applicability
		M (SD)	M (SD)
28	(7) Back up your instructions with logical consequences	4.00 (1.00)	3.48 (0.94)
29	(8) Use blocking for dangerous behaviour	4.12 (0.89)	3.94 (0.75)
30	(9) Use brief interruption for disruptive behaviour	3.27 (1.07)	3.15 (0.87)
31	(10) Use quiet time to deal with misbehaviour;	2.64 (1.22)	2.97 (1.07)
32	(11) Use time-out to deal with serious misbehaviour	2.24 (1.20)	2.79 (1.19)
<b>5 Family Survival Tips</b>			<sup>2</sup>
33	(1) Work as a team	<sup>1</sup>	3.61 (0.97)
34	(2) Avoid arguments in front of your child	<sup>1</sup>	3.30 (0.98)
35	(3) Get support	<sup>1</sup>	3.85 (0.94)
36	(4) Have a break	<sup>1</sup>	3.24 (0.94)
37	(5) Think positive	<sup>1</sup>	3.00 (0.83)
38	<b>Overall evaluation of the training program</b> (1 item)	<b>3.48 (1.09)</b>	<b>3.00 (0.75)</b>

Note: M = mean, SD = standard deviation

<sup>1</sup> Ethical acceptability was not evaluated for this dimension due to expected highly positive convergence

<sup>2</sup> “I consider the recommendation to be practically applicable for families with disabled children”

*Strategies for Managing Misbehaviour.* The ethical acceptability of the 11 strategies from Part 4 of the video was predominantly rated positively with three exceptions: “Use planned ignoring” (M = 3.00), which was evaluated neither positively nor negatively “Use quiet time to deal with serious misbehaviour” (M = 2.64) and “Use time-out to deal with serious misbehaviour” (M = 2.24), which were evaluated negatively (the means ranged between 2.24 and 4.39). As “quiet time” and “time-out” were the only strategies to be evaluated negatively the percentage distributions of the evaluations are reported. The ethical acceptance of “quiet time” was rated as very negative by 21.2% of the sample, by 27.3% as negative, by 24.2% as neither positive nor negative, by 21.2% as positive and by 6.1% as very positive. The ethical acceptance of “time-out” was rated as very negative by 33% of the sample, by 30% as negative, by 21% as neither positive nor negative, by 9% as positive and by 6% as very positive. The practical applicability of all but 4 strategies was predominantly evaluated positively (means of the eleven strategies ranged between 2.79 and 3.94): of these four (“Use diversion to another activity”, “Teach your child to communicate what they want”, “Use quiet time” and “Use time-out”), “Use time-out” was the most negatively evaluated.

*Family Survival Tips.* The five tips presented in Part 5 of the video, which were not rated for ethical acceptability, were predominantly rated positively for their practical applicability except “Think positive” ( $M = 3.00$ ), which was rated neither positively nor negatively (the five means ranged between 3.00 and 3.85).

The following results for the overall evaluation of the SSTP program items in terms of ethical acceptance (Item 38) can be shown (see Table 1): the acceptance of the program was rated on average as positive ( $M = 3.48$ ). Specifically, it was rated as very negative by 6% of the participants, by 9% as negative, by 33% as neither positive nor negative, by 33% as positive and by 18% as very positive; the practical applicability of the program was rated on average as neither positive nor negative ( $M = 3.0$ ) and as very negative by 3% of the participants, by 18% as negative, by 55% as neither positive nor negative, by 24% as positive and by 0% as very positive. The overall evaluation of the program in terms of ethical acceptability was on average clearly less positive ( $M = 3.48$ ) than the evaluation of the individual aspects and strategies averaged over all 32 items ( $M = 4.13$ ) as was the overall evaluation in terms of practical applicability of the program on average clearly less positive ( $M = 3.00$ ) than the evaluation of the individual aspects and strategies averaged over all 37 items ( $M = 3.50$ ).

The results from Items 39-43 of the questionnaire on the social validity of the SSTP relating to the evaluation of global aspects of the SSTP program are summarized in Table 2. The flexibility of the program (Item 41) was rated on average as negative ( $M = 2.55$ ) and the promotion of the development of the child’s independence (Item 40) on average as slightly positive ( $M = 3.06$ ). The practical applicability of the presented strategies for both working parents (Item 41,  $M = 2.42$ ) and single parents (Item 42,  $M = 2.55$ ) was rated on average as negative. Finally, the appropriateness of the presented examples of problem behaviour (Item 43) on average as slightly negative ( $M = 2.93$ ). In summary, the items 39-43 on *global* aspects of the program (see Table 2) were evaluated less positively than the items 1-38 on *individual* aspects and strategies of the program on average (summarized over all 38 items). The students from the sample judged missing flexibility and restricted applicability for working and single parents to be the most critical global aspects of the program.

Table 2 - *Results of the quantitative questionnaire on the social validity of the SSTP: General characteristics of the SSTP program*

<b>Item No.</b>	<b>Items: Global aspects SSTP</b>	<b>M (SD)</b>
39	The presented parenting strategies leave parents and children enough room for flexibility	2.55 (1.03)
40	The presented parenting strategies promote the development of the child's independence	3.06 (1.12)
41	The presented parenting strategies can also be used by working parents	2.42 (1.09)
42	The presented parenting strategies can also be used by single parents	2.55 (1.15)
43	The examples of problem behaviour are appropriate	2.93 (1.12)

Note: M = mean, SD = standard deviation

### *3.2 Results from the qualitative questionnaire on the social validity of the SSTP*

The results of the 15 items are summarized in Table 3 and show attitudes and evaluations towards the program.

(a) The individual key aspects of Positive Parenting presented in the parent video (Item 1) were approved to be appropriate goals by the large majority (81%). However, this evaluation was qualified by criticisms (see Item 2) expressed by a large number of students (64%), stressing that terms like “realistic expectations” or “appropriate (child) behaviour” were not defined exactly enough in the video with the consequence that child's needs could be neglected in favour of parents' egocentric interests.

(b) “Causes of behaviour problems” (Item 3) was evaluated positively as an important topic for parents by a clear majority of 71%. It was criticised by a minority deeming that family's influence on the child was not emphasized enough.

(c) Promoting children's development in terms of individual strategies (Item 4) was appraised as relevant and meaningful for enhancing child's abilities and skills and as usable by the clear majority of 76% of the respondents. However, this affirmative position was qualified (see Items 5 and 6) by about the half of the students (55%), criticizing parenting examples as being too mechanical, indicating a tendency to continuously categorize

child's behaviour as right or wrong, rewarding or punishing, and increasing the risk of neglecting the child's individuality and creativity.

(d) "The strategies of managing misbehaviour (excluding quiet time and time-out)" (Item 7) were evaluated positively only by a minority of 35% as effective and practicable in making daily life more comfortable and easy for all family members. The majority (60%) evaluated these strategies negatively seeing a lack of parental empathy and consideration of the child's individual needs (Item 7). Likewise, the strategies of "Quiet Time" and "Time-Out" (item 8) were evaluated by the great majority (79%) as negative, focusing on repressive and ethically dubious features of time-out procedures. Only 17% of the responders judged these methods to be acceptable. Items 9-11 also relate to "Strategies of managing misbehaviour". The answers to these revealed further critical attitudes towards this part of the video. Almost all respondents (92%) thought that neither the causes of the behaviour problems (Item 9), nor the discussion with the child about reasons for his/her behaviour and alternative behaviours were not presented adequately. Whereas 46% of the respondents criticised that the parenting strategies failed to teach autonomy and independence, focusing too much on conditioning, 50% of students were convinced that children are supported in acquiring self-dependence (item 10). However, 74% saw a risk in the inflexible and dogmatic use of strategies from "managing misbehaviour" (Item 11).

(e) The recommendations presented in Part 5 were evaluated positively by the large majority (85%) as meaningful, effective and practical.

(f) The items 13-15 related to global evaluative aspects of the program. 62% of the students characterized the recommended parenting behaviours (Item 13) as lacking empathy and promoting dependency, whereas 25% of the sample evaluated the parenting behaviour as supporting, loving, and effective. The perceived goals of the Stepping Stones parent training (Item 14) were positively evaluated by 50% of the sample as enhancing self-efficacy and focusing on child acceptance, whereas 46% believed that the goals emphasized too much obedience and thus neglected autonomy. Responding to the question of chances and risks of the program (Item 15), 58% focused on risks, stressing rigid patterns, whereas 25% of the sample focused on chances, stressing empowering children with more autonomy. Overall, the results from the qualitative questionnaire indicate that (1) individual elements of the programs, such as "key aspects", "strategies for promoting development", and "recommendations for family life" were appreciated by the large majority of the students (70 to 85%). However, (2) a significant percentage (50 to 65%) qualified their positive evaluations of individual aspects of the program by criticizing overall features of the program, stressing neglecting child's needs for autonomy, individuality and loving care. Furthermore, (3) the demonstrated use of "managing misbehaviour", specifically of time-out strategies, was criticized by a large majority of about 80%.



Table 3 - Results from the 15 item Qualitative Questionnaire

15-items SSTP Qualitative Questionnaire	%-pos <sup>1</sup> %-neu <sup>2</sup> %-neg <sup>3</sup>	Examples for positive and negative statements
(1) "Part 1: What is Positive Parenting? In Part 1 seven principles (aspects) of Positive Parenting have been described ("ensuring safe, interesting environment" etc., all 7 aspects were presented). Please evaluate the presented principles and give reasons for your judgement"	pos=80.9% neu=0.0% neg=19.1%	<u>pos</u> : "I appreciate the principles as guidelines never to be neglected"; <u>neg</u> : "...very unspecific, the rules in each case are not addressed clearly";
(2) "Please comment on the following statement on the video (Part 1) from a student (from a preliminary study): I think there is too much emphasis on the "correct" behaviour. What is "correct behaviour and how can parents know that the be-haviour they deem as correct is really the best for the child?"	pos=22.7% neu=13.6% neg=63.7%	<u>pos</u> : "I don't agree. I understood that the strategies have to be fitted to the specific situation. They are a framework for very insecure or inexperienced parents and will not harm the child in any way"; <u>neg</u> : "Exactly, that's the point that annoys me most What is the definition of "correct", "realistic expectation", "consequence"? You want a functioning child? It's not about the child - it's about the parents' peace of mind";
(3) "Part 2: Causes of behaviour problems ("genetic and biological make-up", "family environment", "influences from peers, school, and media"). Please evaluate the presented contents and give reasons for your judgement"	pos=71.4% neu=4.8% neg=23.8%	<u>pos</u> : "interesting and useful; non-professionals often don't know these things"; <u>neg</u> : "This part is too short, especially about influences that come from outside the family. The immense impact of parents decreases over time...";
(4) "Part 3: Promoting children's development ("spend quality time with your child" etc., all 14 strategies were presented). Please evaluate the presented strategies and give reasons for your judgement"	pos=76.2% neu=4.8% neg=19.0%	<u>pos</u> : "I think the strategies shown are very good for promoting development; they are reasonable and simply to use"; <u>neg</u> : "The strategies are based on learning theories. However, the question of the right attitude toward the child is not discussed. I think the approach is too mechanical";
(5) "Please comment on the following statement (...): The parenting behaviours demonstrated in Part 3 fail to adequately take into account the children's and parents' individuality and intuition"	pos=36.4% neu=9.1% neg=54.5%	<u>pos</u> : "I disagree; I think the strategies shown are a framework that will be reduced step-by-step (gradually) so that individuality and intuition are promoted"; <u>neg</u> : "I agree – everything seems like a manual for a mechanical toy";

15-items SSTP Qualitative Questionnaire	% -pos <sup>1</sup> % -neu <sup>2</sup> % -neg <sup>3</sup>	Examples for positive and negative statements
(06) "Please comment on the following statement (...): I think the permanent assessment of the child's behaviour in Part 3 is highly problematic: Whatever the child is doing, it has always either to be rewarded or punished for it."	pos=41.0% neu=4.5% neg=54.5%	<u>pos</u> : "I think the program reinforces constructive behaviour that is necessary for the child's development and reduces destructive behaviour by ignoring it ..."; <u>neg</u> : "I agree. With this program children are trained only to function";
(07) "Part 4: Managing misbehaviour ["use diversion to another activity" etc.; 9 of the 11 strategies are included here; "quiet time" and "time out is analyzed separately, see item 08]. Please evaluate the presented strategies and give reasons for your judgement".	pos=60.0% neu=5.0% neg=35.0%	<u>pos</u> : "Overall I think the strategies are very good, because their goal is to ease the live)s of everyone involved"; <u>neg</u> : "These strategies as they are shown are all unacceptable. They do attain the goal in some cases. The needs of the child are not further considered. Threats and punishments come first.";
(08) "Please evaluate the presented strategies Quiet Time and Time-out and give reasons for your judgement"; "Please comment on the following statement (...) on the video, Part 4: Quiet Time and Time Out are good for bringing peace to both parents and children".	pos=16.7% neu=4.2% neg=79.1%	<u>pos</u> : "I think its good because it's practical" (...) I agree because both parties get time to to think"; <u>neg</u> : "... reminds me a lot of locking up children and of parental arbitrariness";
(09) "Please comment on the following statement (...) on the video, Part 4: The possible causes of the child's behaviour are not discussed adequately".	pos=8.3% neu=0.0% neg=91.7%	<u>pos</u> : "This statement only partly true, for it is said "teach your child to communicate what it wants and feels [thus, the child learns to communicate its needs and the reasons for its misbehaviour]"; <u>neg</u> : "Not much is spoken to the child about reasons and possible alternatives – a specific behaviour is set and demanded That's a major flaw of the program".
(10) "Please comment on the following statement (...) on the video, Part 4: The child is disciplined rather than brought up to be more independent and self-responsible."	pos=50.0% neu=4.2% neg=45.8%	<u>pos</u> : "I don't agree because the program helps the child to become independent, e.g. by the strategy "Teach your child to communicate what it wants"; <u>neg</u> : "That's right, the child is simply conditioned "
(11) "Please comment on the following statement (...) on the video, Part 4: The recommended strategies are presented in a dogmatic way. As a consequence, there is a risk of implementing parental strategies uncritically and inflexibly."	pos=21.7% neu=4.4% neg=73.9%	<u>pos</u> : "I don't agree because parents are offered a lot of for implementing strategies"; <u>neg</u> : "That's right! It looks like there are no alternatives";

15-items SSTP Qualitative Questionnaire	%-pos <sup>1</sup> %-neu <sup>2</sup> %-neg <sup>3</sup>	Examples for positive and negative statements
(12) "Part 5: Family survival Tips ("work as a team" etc, the five tips were listed). Please evaluate the recommendations and give reasons for your judgement."	pos=85.0% neu=5.0% neg=10.0%	<u>pos</u> : "They are meaningful and effective because they can be put into practise"; <u>neg</u> : "Sounds pretty good, but most of them can't be realised";
(13) How would you characterise the recommended parenting behaviours?	pos=25.0% neu=12.5% neg=62.5%	<u>pos</u> : "Promoting, positive, clear, understandable for the child; supporting and caring"; <u>neg</u> : "It looks a bit unsympathetic, similar to an operation instruction";
(14) Please describe in your own words the goals of the Stepping Stones parent training	pos=50.0% neu=4.2% neg=45.8%	<u>pos</u> : "To raise awareness for systematic effects in education (e. g. consequent behaviour) – to raise awareness for self-efficacy; - to accept the child as he/she is"; <u>neg</u> : "Well functioning disabled children, who reduce parents' stress level. Increased autonomy, greater independence of both parties, and appropriate child behaviour fade into the background";
(15) What chances and risks do you see in this parent training?	pos=25.0% neu=16.7% neg=58.3%	<u>pos</u> : "children are enabled to live an independent life" <u>neg</u> : "the child with his/her unique behaviour is pressed into a rigid pattern";

Notes

<sup>1</sup> Categories of "positive" and "very positive" have been summarized.

<sup>2</sup> Neutral (neither positive nor negative, partly-partly).

<sup>3</sup> Categories of "negative" and "very negative" have been summarized; "positive" means: "an evaluation in favour of the program"; due to some missing/not analyzable data the number of respondents varies between 22 and 24.

### 3.3 Correspondence between the Quantitative (QN) and Qualitative (QL) Questionnaires

Pearson correlations between the variables in the two questionnaires were carried out in order to analyse the correspondence between the quantitative and qualitative questionnaires. The selected variables from the quantitative questionnaire include the scales (a) "ethical acceptability of key aspects-QN" (computed by summarizing across all 7 items, see Table 1, Mean (M) = 4.54, SD = 0.45), (b) "ethical acceptability of promoting development-QN" (summarized across all 14 items, Table 1, M = 4.37, SD = 0.44), (c) "ethical acceptability of managing misbehaviour-QN" (summarized across all 11 items, Table 1, M = 3.59, SD = 0.71), and (d) "global evaluative aspects of

SSTP-QN” (summarized across items 1, 2 and 5 in Table 2 and item “overall evaluation of the training program in terms of ethical acceptability”, Table 1,  $M = 3.01$ ,  $SD = 0.85$ ). The selected variables from the qualitative questionnaire included the scales (a) “evaluation of key aspects-QL” (summarized across item 1 and 2, Table 3,  $M = 2.98$ ,  $SD = 1.12$ ), (b) “evaluation of promoting development-QL” (summarized across items 4 to 6, Table 3,  $M = 3.03$ ,  $SD = 1.26$ ), (c) “evaluation of managing misbehaviour-QL” (summarized across items 7-11, Table 3,  $M = 2.72$ ,  $SD = 0.67$ ), and (d) “global evaluative aspects of SSTP-QL” (summarized across items 13-15, Table 3,  $M = 2.63$ ,  $SD = 1.35$ ).

The results of the correlation analyses revealed positive, for the most part significant, correlations between the variables of the quantitative (QN) and qualitative (QL) questionnaires. Specifically: (a) the scale “ethical acceptability of key aspects-QN” correlated nonsignificantly ( $r = 0.28$ , ns) with “ethical acceptability of key aspects-QL” and significantly ( $r = 0.54$ ,  $p < .01$ ) with “global evaluative aspects of SSTP-QN”; (b) the scale “ethical acceptability of promoting development-QN” correlated significantly with “evaluation of promoting development-QL” ( $r = 0.58$ ,  $p < .01$ ) and “global evaluative aspects of SSTP-QN” ( $r = .71$ ,  $p < .01$ ); (c) the scale “ethical acceptability of managing misbehaviour-QN” correlated significantly with “evaluation of managing misbehaviour-QL” ( $r = .49$ ,  $p < .05$ ) and with “global evaluative aspects of SSTP-QN” ( $r = .63$ ,  $p < .01$ ); (d) the scale “global evaluative aspects of SSTP-QN” correlated significantly with the corresponding scale “global evaluative aspects of SSTP-QL” ( $r = .73$ ,  $p < .01$ ). In sum, all correlations were significant at least at the 5-percent level, except the correlation between the two “acceptability of key aspects” variables, possibly due to ceiling effects. Thus, in general the results indicate sufficient concordance between the two measurement instruments.

## 4. Discussion

The aim of the present study was to assess central aspects of the social validity of the parent training program Stepping Stones Triple P.

### 4.1 Sample of master level students

The study was carried out with a sample of paraprofessionals consisting of master level students of psychology. These can be considered to be a relevant group for a first-step social validation in a new sociocultural environment because it can be assumed that the great majority of the participants will be working as professionals in the health sector and be involved in preventative and rehabilitative programs in the near future. Further, as the members of this group are as yet not bound and obliged to therapy schools - such as behavioural, psychodynamic or systemic-family orientated approaches - they may be less biased and more open-minded towards evalua-

tion studies like the present one. Nevertheless, the inclusion of experts having clinical expertise with children with disabilities is absolutely essential for a second-step social validation, in order to ensure comprehensive judgments based on real-life experiences with clients and their families, and with various diagnostic subgroups. Overall, the analysis reveals that seemingly there was no general anti-behaviouristic bias, as has been reported to be characteristic for some part of students and professionals of Psychology in Germany (Lueck, 1991), shown by this sample of students. For, typical behaviouristic strategies of behaviour shaping, such as “Use ask, say, do” or “Teach backwards”, of contingency management, such as “Use Behaviour Charts” or of “antecedent interventions”, such as “Set up activity schedules” were evaluated as moderately to highly positive in terms of ethical acceptability. Negative evaluations focused clearly on the two timeout procedures.

#### 4.2 Overall evaluation of the program

Overall, the central criterion of social validity, ethical acceptability, was evaluated positively. This result is in line with results of the studies from Whittingham *et al.* (2006), Roberts *et al.* (2006) and Plant and Sanders (2007b), which were carried out on parents of children with developmental disabilities. However, the practical applicability of the program was evaluated overall only neutrally in this study. It is possible that the practical applicability of the program was not evaluated positively because the participants saw a lack of consideration of single and working parents and did not judge the Australian family model with the mother apparently being a housewife and solely responsible for the parenting to be generally valid in the German context. This point could be relevant in other European countries. In contrast, the practical applicability of the SSTP program was evaluated more positively in the Whittingham *et al.* (2006) study from Australia.

The *overall* evaluation of the ethical acceptance was not as positive as the mean acceptance of the *individual* strategies. A similar result can be seen to a lesser degree for practical applicability. That the overall evaluation of the program was less positive than the average evaluation of the individual strategies on both dimensions could be due to the following factors: a) the overall evaluation was made at the end of the video presentation and was thus biased by salient negatively perceived individual strategies, such as the time-out strategies (see below); (b) doubt about the implementation of the program in German family life; (c) the critical evaluation of the flexibility of the program for both parents and children; (d) critical evaluation of the program quality with too little emphasis on empathy, enjoyment, self-determination, independence, and consideration of the child’s individual needs and with too much emphasis on control, obedience and dependency.

#### 4.3 Evaluation of individual parenting aspects and strategies

The results revealed the key social validity criterion of ethical accept-

ability was evaluated positively for a total of 29 of the 32 individual parenting aspects and strategies. This overall positive result is in line with the results of the Whittingham *et al.* (2006) and Roberts *et al.* (2006) studies. The only strategy to be evaluated neither positively nor negatively was “using planned ignoring for minor problem behaviour”. This result is also consistent with the results of the Whittingham *et al.* (2006) study. “Planned ignoring” was viewed critically by the parents in this study because it did not take into consideration the causes of children’s behavioural problems. The strategies of “quiet time” and “time-out”, which were evaluated negatively, will be discussed in the next section.

#### 4.4 Evaluation of time-out strategies

The strategies “quiet time to deal with misbehaviour” and “time-out to deal with serious misbehaviour” are both “time-out from positive reinforcement” strategies and are classified in the literature as “exclusionary time-out” (Parrish, 1994) or simply as time-out strategies. They were the only strategies in the SSTP program to be evaluated negatively with regard to their acceptance. “Time-out” was evaluated as negative by two thirds of the participants and “quiet time” by approximately half. There were also many critical negative comments in the qualitative questionnaire relating to these strategies. These could be classified as (a) general ethical arguments, for example, “restricting the development of the child’s personality”, (b) children’s rights topics, for example, “limiting freedom through restrictive punishments that limit the child’s movement”, and (c) professional-ethical arguments, for example, “endangering the child’s health by accepting the risk of negative consequences for the child’s development” and “restricting the right for the best possible treatment”.

According to the authors (Sanders *et al.*, 2003a, pp. 29-30), quiet time involves removing the child from the activity in which the problem behaviour occurred and having him/her sit quietly on the edge of the activity for a short time (e.g., in the corner of the room). The criterion for using time-out is when the child does not stay in quiet time or as a consequence for temper outbursts or serious misbehaviour such as hurting others. In time-out the child is put in another room away from everyone else and kept there for a short time. The room should be uninteresting yet safe, with good lighting and ventilation. The door is only closed if the child does not stay in the room. Time-out and quiet time is ended when then the child has remained quiet for the agreed time (e.g., one minute).

The overall negative evaluation of the time-out strategies in the qualitative questionnaire is consistent with the results of the Whittingham *et al.* (2006) study, where a portion of the parents with children with autism evaluated these strategies critically because they ignore the activating events and stabilizing factors of the problem behaviour and make the implementation of alternative (non-aversive) developmentally adequate methods (e.g.,

“social story” approaches) more difficult. In addition, caution with regard to the use of the time-out strategies for the problem behaviour of individuals with disabilities was reported in an Australian review of the SSTP method (Wiese *et al.*, 2005): “Again, identical to Triple P (standard program), the use of time-out may be of concern to DADHC [Department of Ageing, Disability & Home Care, Australia] given its policy on Restricted Practices (Behaviour Intervention and Support Policy, 2003, p. 49). In contrast to these results, in two clinical studies from Roberts *et al.* (2006) and Whittingham *et al.* (2009b), time-out strategies were evaluated predominantly as positive (“helpful”) by parents of children with mental retardation and autism.

The low social acceptance of the time-out methods in the current study may be due to the fact that there was a lack of a convincing context for using these strategies as they were not presented as being part of a global educational-therapeutic concept. There is general agreement on this concept in the literature (Bregman, Zager, & Gerdtz, 2005) and it has four main features:

(1) *Seriousness of the problem behaviour as a criterion for indication:* There is general agreement that aversive methods such as time-out should only be used when the problem behaviour is serious and destructive, and endangers the health of the client/ patient or family member, such as physical aggression, intentional damage to property, tantrums, and specific types of self-destructive behaviour (Parrish, 1994; Carr, 1998; Scott, 1998). However, the video booklet and workbook state that the time-out strategies are recommended not only for serious misbehaviour, but also for everyday problems of obedience (Sanders *et al.*, 2003a, p. 29-30). Furthermore, the exit conditions are formulated conditionally (peaceful behaviour for a set period of time) so that the time-out periods can be of a considerable duration.

The time-out strategies in the video were applied in four examples (see Table 4). In two of them, the misbehaviours consisted in not following the mother’s instruction (Example 1), such as to stop throwing toys on the floor or to put on one’s shoes (Example 3), which are comparatively minor problem behaviour. In the other two, the reasons for punishment were not clear (Example 2) or not reported (Example 4), respectively.

(2) *Urgency of the intervention:* It is not clear in the video and workbook that the restrictive interventions are to be used when they are urgently needed, unavoidable (Bregman *et al.*, 2005; Harris, 1998) and according to the principle of the “least restrictive alternative” (Rojahn & Weber, 1996; Bernard-Opitz, 2007), where all other available alternatives with less restrictiveness have been exhausted (Parrish, 1994). Furthermore, it is not adequately clear whether a “functional behavioural analysis” was previously carried out or whether the time-out strategy was carried out within a comprehensive treatment approach for this problem behaviour (Bregman *et al.*, 2005).

In all four examples (see Table 4), video and workbook failed to indicate the urgency of the situations and to document results from functional behavioural analysis. For example in the case of Michaela (Table 4, No. 1),

what are possible causes and functions of “throwing toys on the floor”? Is the child bored with the game? Or enjoying the body movement? Or fascinated by the noises? Or wanting to annoy her mother?

(3) *Analysis of possible detrimental effects*: Possible detrimental effects are not sufficiently described, as they are by Parrish (1994), Harris (1998) and Howlin (1998a, b). These include taking offence, loneliness and feeling excluded. Further unwanted consequences could be “modelling inappropriate behaviour” and “suppressing non-targeted behaviour” (Parrish, 1994). The parents need to be informed of such detrimental consequences (“informed consent”, Parrish, 1994).

(4) *Ethical considerations and monitoring*: The video and workbook failed to mention that time-out strategies are highly controversial methods that are only to be used in families and institutions in the short-term, when they are strongly indicated, and when they are continually monitored and are carried out under professional supervision (Parrish, 1994; Howlin, 1998a; Bregman *et al.* 2005).

Table 4 - *Exemplary scenes from the SSTP-parent video showing use of time out strategies*

Description of the scenes (Source: Parent Video, Part 4, Managing Misbehaviour)
(1) Michaela, a girl in preschool age with Down Syndrome is playing with a large pile of play dough. She is trying to punch out some play dough figures with a form. However, the form seems more interesting to her than using it with the clay. She explores it and then throws it off the table. Obviously she is not doing this to annoy anyone or to misbehave but to try something out. Her mother (women next to her) urges her to keep the form on the table. Michaela does not react to this, it seems like she is too absorbed into her exploration. So she throws another figure off the table. Now her mother punishes her by putting her into quiet time. After time is up and Michaela is allowed to return to the table, her mother praises her as she is bumping the form repeatedly into a massive pile of clay. All her curiosity and interest seems to be gone. The scene looks like there 'is only one right way to play with this form and Michaela is forced to do it.
(2) A toddler on his mothers arm, seemingly with an intellectual disability, is carried around while his mother is taking to his room. The speaker in the video tells us "a toddler's playpen can be used as the quiet place for the age of about 18 months and onwards". However, it remains totally unclear what the toddler really did and why. It' is almost obvious that he doesn't even understand why he is brought to his playpen.
(3) Justin, a boy in preschool age, refuses to obey his mother's request: "Justin, it's time for pre-school. Put your shoes on, please". He refuses with "No!" and throws away the shoes his mother has handed to him. His mother brings his shoes back and repeats her request: "It's time for pre-school, you have to put your shoes on", handing the shoes to him again. Again, Justin throws the shoes away. Mother: "Okay, it's time for quiet time. Come on!" She takes his hands pulling him away from his rocking vehicle (commentary: "In this example quiet time is used at first.") Mother: "You need to sit here quietly for one minute" (commentary: "And when the child doesn't stay in quiet time the parent uses time-out as a backup"). Justin does not stay quiet and as a result he has to go to time out. Mother: "Justin, you haven't stayed in quiet time, it's time for time out. Come on". In this example, it is not reported whether alternative, less restrictive strategies such as "response cost" in the context of behaviour charts had been administered before, and what the possible reasons for complying with mother's requests might be. Overall, the scene looks staged.
(4) Jay, a boy in preschool age, is sent to by his mother downstairs to sit in time-out on a stool next to the washing machine. Mother: "Jay when you've been quiet for one minute you may come out of time out." After a while, mother takes him back, saying: "Jay you have been in time out for one minute you may come out of time out now." In this scene, the cause for sending the boy to time-out is not reported nor is said what other and less restrictive treatments had been used before.



*4.5 Inflexible and over-directive use of parenting methods*

A further factor that may have lead to the critical and partly negative evaluation of the program is the preponderance and inappropriate use of “traditional behavioural methods”, drawing primarily from operant learning theories, stressing permanent external consequences and tending to an over-directive interaction style in some places in SSTP compared with “contemporary behavioural methods” (see Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006, pp. 118-119), in which more weight is placed on developmental aspects, intrinsic motivation, self-initiative and facilitative interaction style. These approaches are considered very important for secondary and tertiary prevention of developmental disabilities (National Professional Resources & Paul H. Brookes, 2004; Prizant & Wetherby, 2005).

An exemplary scene from the parent video, which was critically commented upon by some students, can illustrate this point (see Part 1 of the video, Aspects of Positive Parenting, Sanders *et al.*, 2003a). The scene is designed to demonstrate the third key aspect of positive parenting, “using assertive discipline”, defined as “being decisive and responding quickly when your youngster is misbehaving and teaching him/ her to behave in an acceptable way”:

Table 5 - Results from the 15 item Qualitative Questionnaire

Description of the scene (Source: SSTP parent video, Part 1)
<p>A boy of preschool age, supposedly with intellectual disability, is playing alone on the floor with some toys, hammering a robust-looking toy boat with a snail figure on top. He looks concentrated and fascinated in his activity, showing no signs of aggressive or destructive intention. However his play is interrupted immediately by his mother and he is scolded as follows: "We don't hit the boat with the hammer, do we? What do we hit with the hammer? What do we use the hammer for?" After the boy answered "For the bridge" (a wooden toy work bench next to him), his mother praised him, "Good boy, - you hit the bridge with the hammer". Afterwards the boy shows full compliance by hammering the wooden pegs into the work bench.</p>

---

Figure 1 - *Illustration of the scene from Part 1 of SSTP video, described in Table 5*

---



---

The boy's activity could however be seen as being developmentally appropriate functional play activity rather than as misbehaviour. In this case the mother could have responded in a more facilitative and participating interaction style as a play partner.

#### *4.6 Appropriateness of the research instruments*

The combination of quantitative and qualitative methods applied in this study is known as the "middle ground" approach (Prizant & Wetherby, 2005), which is a proven approach in the interdisciplinary field of developmental disabilities. The analysis of the results shows that the two methods are complimentary. The ratings from the quantitative instrument can be better understood when viewed in the context of the answers in the qualitative questionnaire and vice versa.

#### *4.7 Limitations of the study*

The following factors need to be considered when interpreting the results of this study: (1) *Sample size*: The sample in this study was relatively small with 33 participants. (2) *Subjects*: the sample consisted of master level students of psychology. The participants were asked to take part in the context of an obligatory lecture and thus the sample is an availability sample. For this reason, the representativeness of our sample for the whole population of paraprofessionals of the same discipline or indeed other similar disciplines (education, medicine, social work.) cannot be assumed. (3) *Clinical expertise*: Furthermore, the master level students had limited clinical experience required to accurately evaluate the practical applicability of developmental disability intervention methods in families.

## 5. Conclusion

Under consideration of the methodological limitations discussed above, the results of this first empirical investigation of the social validity of the Stepping Stone parenting program in German speaking countries are two-fold:

(1) Overall, the results support the assumption of a positive social validity. On the key dimension of ethical acceptability, the global evaluation was on average positive, with 52% of the participants evaluating it positively and only 19% negatively. This result is consistent with results from some studies in the English-speaking world. (2) However, there were restrictions to the social validity of some specific aspects of the program. These primarily concerned the time-out strategies. The ethical acceptability of the time-out strategy was evaluated negatively by 64% of participants and arguments relating to professional ethics, children's rights and educational principles were given. This result is also consistent with some studies from the English-speaking literature. Furthermore, there was a possible halo effect in the evaluations, whereby the negative evaluation of the time-out strategies lead to a less positive global evaluation of the program. Contemporary behavioural concepts of the child as an active, intrinsically motivated being who experiences enjoyment have been given less weight in the SSTP program in several cases compared to traditional behavioural concepts of the child as a passive, mainly externally controlled being whose behaviour has always to be reinforced, extinguished or punished.

As a consequence, it is recommended that the SSTP program be partially revised. The following modifications are suggested: (1) The sections relating to exclusionary time-out methods in the parent video and family workbook ought to be overworked thoroughly. Time-out should be marked more clearly as a unique and last-resort intervention, to be used only if all less restrictive methods have failed, and, in addition, all three criteria for indication "seriousness of behavior", "urgency for intervention", and "analysis of possible harmful consequences for child and caretakers" have been met. Thus, both time-out strategies should be unequivocally presented as educational procedures standing *not* on the same level as the other nine methods presented in "Strategies for Managing Misbehaviour" (see table 1). (2) All four examples of implementing time-out methods in the parent video, Part 4 (described in table 4), should be removed and replaced by more appropriate instances reflecting criteria for indication. (3) In Part 1 of the parent video, the scene with the child playing with the boat (described in table 5) should be eliminated and replaced by an example taking in account developmental functioning and needs of a child with intellectual disability more thoroughly. (4) In Part 1 and Part 3 of the parent video and in Chapters 3 and 4 of the family workbook, stronger emphasis should be put on "positive antecedent components" (Roberts, Tingstrom, Olmi, & Bellipani, 2008), such as "effective instruction delivery" including visual support methods and related "structured teaching"

strategies (Mesibov & Shea, 2010) addressing in particular the specific needs of children with intellectual, autism spectrum, and related developmental disabilities. These positive antecedents may obviate the need for highly restrictive methods in some cases (Roberts *et al.*, 2008). Further, critical incidents resulting from incorrect use of time out may be prevented.

In this way, the interdisciplinary professional and common acceptance of the program can be further improved.

The implementation of the preventative SSTP parenting program in German-speaking and other countries reflects the urgent need in society for such a program. The particular advantages of the SSTP program are that it has the status of preliminary evidence, and is international, interdisciplinary, easily accessible due to Triple P's trans-regional structure, suitable for children with different developmental disabilities and its use has been controlled by a licensing system.

Further steps of research should expand to various groups of clinical professionals, paraprofessionals, and nonprofessionals, e. g. parents, who have everyday experience with children with disabilities and to investigate the program's specific efficacy for various diagnostic categories.

## References

- American Psychological Association (2002). *Ethical Principles of Psychologists and Code of Conduct*. Retrieved February, 10, 2009, from <http://www.apa.org/ethics/code2002.html>.
- Batshaw, M. L. (Ed.) (1994). *Children with disabilities* (fourth edition). Baltimore: Brookes.
- Bernard-Opitz, V. (2007). *Children with Autism Spectrum Disorders*. Austin, TX: Pro ed.
- Bregman, J. D., Zager, D., & Gerdtz, J. (2005). Behavioural interventions. In F. R Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and developmental disorders* (3rd Ed., Vol. 2, pp. 897-924). Hoboken, NJ: Wiley.
- Callahan, K., Henson, R. K., & Cowan, A. K. (2008). Social validation of evidence-based practices in autism by parents, teachers, and administrators. *Journal of Autism and Developmental Disorders*, 38, 676-692.
- Carr, J. (1998). Children with learning disabilities. In P. Howlin (Ed.) *Behavioural approaches to problems in childhood* (pp. 78-94). London: Cambridge University Press.
- Chambless, D. L. & Hollon, S. D. (1998). Defining empirically supported therapies. *Journal of Clinical and Consulting Psychology*, 66, 7-18.

- Harris, J. (1998). Cerebral Palsy. In P. Howlin (Ed.) *Behavioural approaches to problems in childhood* (pp. 136-151). London: Cambridge University Press.
- Heinrichs, N., Hahlweg, K., & Doepfner, M. (Eds.) (2006). *Strengthening families: Evidence-based approaches to support child mental health*. Muenster, Germany: Verlag fuer Psychologie.
- Howlin, P. (Ed.) (1998a). *Behavioural approaches to problems in childhood*. London: Cambridge University Press.
- Howlin, P. (1998b). *Children with autism and Asperger Syndrome: A guide for practitioners and carers*. New York: Wiley.
- Loesel, F. (2006). *Bestandsaufnahme und Evaluation von Angeboten im Elternbildungsbereich – Abschlussbericht [Final evaluative report on parent education and parenting interventions provided by health care institutions]* Bundesministerium fuer Familie, Senioren, Frauen und Jugend [Federal Ministry for Family, Seniors, Women, and Youth], Berlin, Germany. Retrieved February 12, 2009 from <http://www.bmfsfj.de/doku/elternbildungsbereich/pdf/abschlussbericht2006.pdf>.
- Lueck, H. E. (1991). *Geschichte der Psychologie [History of psychology]*. Stuttgart: Kohlhammer.
- Mah, J. W., & Johnston, C. (2008). Parental social cognitions: Considerations in the acceptability of and the engagement in behavioural parent training. *Clinical Child Family Psychology Review, 11*, 218-236.
- Mesibov, G. B., & Shea, V. (2010). The TEACCH program in the area of evidence-based practice. *Journal of Autism and Developmental Disorders, 40*, 570-579.
- National Professional Resources & Paul H. Brookes Publishing (2004). *Autism Spectrum Disorders & the SCERTS™ model: A comprehensive educational approach* [DVD]. Baltimore, MD: Author.
- Nowak, C., & Heinrichs, N. (2008). A comprehensive meta-analysis of Triple P-Positive Parenting Program using hierarchical linear modeling: Effectiveness and moderating variables. *Clinical Child and Family Psychology Review, 11*, 114-144.
- Office of the United Nations High Commissioner for Human Rights (2002). *Convention on the Rights of the Child*: Adopted from U.N. General Assembly, 1989; entry into force: 1990. Retrieved February 12, 2009, from <http://www.unhchr.ch/html/menu3/b/k2crc.htm>.
- Oneal, B. J., Reeb, R. N., Korte, J. R., & Butter, E. J. (2006). Assessment of home-based behaviour modification programs for autistic children: reliability and validity of the behavioural summarized evaluation. *Journal of Prevention and Intervention in the Community, 32* (1-2), 25-39.

- Parrish, J. M. (1994). Behaviour Management: Promoting adaptive behaviour. In M. L. Batshaw (Ed.), *Children with disabilities* (4th Ed., pp. 657-686). Baltimore, MA: Brookes.
- Plant, K. M., & Sanders, M. R. (2007a). Predictors of caregiver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research*, *51*, 109-124.
- Plant, K. M., & Sanders, M. R. (2007b). Reducing problem behaviour during caregiving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities*, *28*, 362-385.
- Prizant, B. M., & Wetherby, A. M. (2005). Critical issues in enhancing communication abilities for persons with autism spectrum disorders. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and developmental disorders* (3rd Ed., Vol. 2, pp. 925-945). Hoboken, NJ: Wiley.
- Prizant, B. M., Wetherby, A. M., Rubin, E., Laurent, A. C., & Rydell, P. J. (2006). *The SCERTS: A comprehensive educational approach for children with autism spectrum disorders* (Vol. 1, Assessment). Baltimore, MD: Brookes.
- Probst, P. (2009). Literatur-Review zur Validität des präventiven Elterntrainings Stepping Stones Triple P [Literature review on the validity of the Stepping Stones Triple P program]. *Praxis der Kinderpsychologie und Kinderpsychiatrie*, *58*, 351-367.
- Reichow, B., Volkmar, F. R., & Cicchetti, D. V. (2008). Development of evaluative method for evaluating and determining evidence-based practices in autism. *Journal of Autism and Developmental Disorders*, *38*, 1311-1319.
- Roberts, D. S., Tingstrom, D. H., Olmi, D. J., & Bellipani, K. D. (2008). Positive antecedents and consequent components in child compliance training. *Behavior Modification*, *32*, 21-38.
- Roberts, C., Mazzucchelli, T. G., Studman, L. J., & Sanders, M. R. (2006). Behavioural Family Intervention for Children with Developmental Disabilities and Behavioural Problems. *Journal of Clinical Child and Adolescent Psychology*, *35*, 180-193.
- Rojahn, J., & Weber, G. (1996). Geistige Behinderung [Intellectual disability]. In J. Margraf (Ed.), *Lehrbuch der Verhaltenstherapie [Textbook on behaviour therapy]* (Vol. 2, pp. 401-413). Berlin, Germany: Springer.
- Rossi, P. H., Lipsey, M. W., & Freeman, H. E. (2004). *Evaluation. A systematic approach* (7th Ed.). London: Sage.
- Sanders, M. (2008). Triple-P-Positive Parenting Program as a public health approach to strengthening parenting. *Journal of Family Psychology*, *22*, 506-517.

- Sanders, M. R., Mazzucchelli, T. G., & Studman, L. J. (2003a). *Stepping Stones Triple P - A survival guide for families with a Child who has a disability* [DVD]. Brisbane, Australia: Triple P International.
- Sanders, M. R., Mazzucchelli, T. G., & Studman, L. J. (2003b). *Stepping Stones Triple P - A survival guide for families with a Child who has a disability* [Booklet]. Brisbane, Australia: Triple P International.
- Sanders, M. R., Mazzucchelli, T. G., & Studman, L. J. (2003c). *Stepping Stones / Triple P family workbook*. Brisbane, Australia: Triple P International.
- Sanders, M. R., Mazzucchelli, T. G., & Studman, L. J. (2004a): Stepping Stones Triple P: The theoretical basis and development of an evidence-based positive parenting Program for families with a child who has a disability. *Journal of Intellectual & Developmental Disability*, 29, 265-283.
- Sanders, M. R., Mazzucchelli, T. G., & Studman, L. J. (2005). *Stepping Stones Triple P: Überlebenshilfe für Eltern von Kindern mit einer Behinderung [A survival guide for families with a Child who has a disability]* [VHS Video] (Families International Pty Ltd; German translation by PAG Institut für Psychologie AG). Muenster: Verlag fuer Psychotherapie.
- Sanders, M. R., Ralph, A., Sofronoff, K., Gardiner, P., Thompson, R., & Dwyer, S. (2008). *Every family: A population approach to reducing behavioural and emotional problems in children making the transition to school*. *Journal of Primary Prevention*, 29, 197-222.
- Sanders, M. R., Turner, K. M. T., & Markie-Dadds, C. (2004b): *Stepping Stones / Triple P Gruppenarbeitsbuch für Eltern von Kindern mit Behinderungen* (German translation by PAG Institut für Psychologie). Muenster, Germany: Verlag fuer Psychotherapie.
- Scott, S. (1998). Conduct disorder. In P. Howlin (Ed.) (1998a) (pp. 1-27).
- Thomas, R., & Zimmer-Gembeck, M. J. (2007). Behavioural outcomes of Parent-Child Interaction Therapy and Triple P-Positive Parenting Program: A review and meta-analysis. *Journal of Abnormal Child Psychology*, 35, 475-495.
- Tonge, B., Brereton, A., Kiomall, M., Mackinnon, A., King, N., & Rinehart, N. (2006). Effects on parental mental health of an education and skills training program for parents of young children with autism: a randomized controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45, 561-569.
- Whittingham, K., Sofronoff, K., & Sheffield, J. K. (2006). Stepping Stones Triple P: A pilot study to evaluate acceptability of the program by parents of a child diagnosed with an Autism Spectrum Disorder. *Research in Developmental Disabilities*, 27, 364-380.

Whittingham, K., Sofronoff, K., Sheffield, J., & Sanders, M. R. (2009a). Stepping Stones Triple P: An RCT of a Parenting Program with Parents of a Child Diagnosed with an Autism Spectrum Disorder. *Journal of Abnormal Child Psychology*, 37, 469-480.

Whittingham, K., Sofronoff, K., Sheffield, J., & Sanders, M. R. (2009b). Behavioural family intervention with parents of children with ASD: What do they find useful in the parenting program Stepping Stones Triple P? *Research in Autism Spectrum Disorders*, 3, 702-713.

Whittingham, K., Sofronoff, K., Sheffield, J., & Sanders, M. R. (2009c). Do parental attributions affect treatment outcome in a parenting program? An exploration of the effects of parental attributions in an RCT of Stepping Stones Triple P for the ASD population. *Research in Autism Spectrum Disorders*, 3 (1), 129-144.

Wiese, M., Stancliffe, R., & Hemsley, B. (2005). Review of positive behaviour support programs for families: *Final report, prepared for the Department of Ageing, Disability and Homecare (DADHC) by the Centre for Developmental Disability Studies*, Sydney, Australia. Retrieved February 10, 2009 from <http://www.dadhc.nsw.gov.au/NR/rdonlyres/A228AA8A-8A20-4058-AAA0-D82C0E37F339/1390/ReviewofPositiveBehaviourSupportProgramsforFamilie.pdf>.



## End-of-life decision-making: a descriptive study on the decisional attitudes of Italian physicians

Claudio Lucchiari,<sup>1</sup> Marianna Masiero,<sup>2</sup> Gabriella Pravettoni,<sup>3</sup>  
Gianluca Vago<sup>4</sup> & Robert L. Wears<sup>5</sup>

### Abstract

*The research on medical decision-making is growing in three main directions: emergency treatment, treatment of chronic disorders, palliative care. The increasing occurrence of chronic diseases, in particular, cancer, has generated a new interest in decision-making procedures in this medical domain. Furthermore, the role of physicians working in different and complex settings and the role of patients and informal caregivers, who are supposed to play an active part in the treatment flow, are now important subjects of research in all parts of the world.*

*In this framework, we conducted a survey on Italian physicians concerned with end of life care. The aim of this study was to describe which factors might influence the decision-making style in this context.*

*Our data clearly showed that the medical decision-making process in incurable illnesses represents a complex and delicate context. Several modulating factors are present in order: medical, ethical, social, and cultural. Physicians, in formulating their own therapeutic decisions, seem to be influenced by three key elements: the patients' need for information and treatment involvement; the interaction between survival time and quality*

\* Received: 30 September 2009, Revised: 10 February 2010, Accepted: 30 March 2010.

<sup>1</sup>Department of Social and Political Studies, University of Milan, Via Conservatorio 7, 20122 Milano. E-mail: claudio.lucchiari@unimi.it

<sup>2</sup>Department of Social and Political Studies, University of Milan. E-mail: marianna.masiero@unimi.it

<sup>3</sup>Department of Social and Political Studies, University of Milan. E-mail: gabriella.pravettoni@unimi.it

<sup>4</sup>Department of Social and Political Studies, University of Milan. E-mail: gianluca.vago@unimi.it

<sup>5</sup>Emergency Medicine Department, University of Florida. E-mail: wears@ufl.edu

*of life, and the role of the informal caregiver (the family). Future research will be required to better understand both patients' and physicians' needs in this critical domain.*

**Keywords:** Decision-making, Patient, Role of caregiver, End of life decision

## 1. Introduction

Shared medical decision-making is generally defined as an ideal way of handling decision-making in medical settings (Charles, Gafni, & Whelan, 1997). Though the generalities of this method are largely accepted, the basic shared decision making principles are not really always applied. There are many different reasons for this dichotomy between the practical, conceptual and also moral origins, especially in the case of terminally ill people. The present descriptive study is going to examine some of these reasons pointing out a physician's behavior when facing clinical choices concerned with one's end of life. This examination was performed in order to better realize the way a medical decision is made from the point of view of a general medical decision-making study, which involves an increasingly growing number of specialists in different fields (physicians, psychologists, sociologists and others). The decision-making studies are nowadays applied in various clinical fields like emergency medicine, treatment of chronicle diseases and palliative care. This last element is strictly correlated with the particularly delicate subject of the end of life, where medical decisions of a technical character deal with its emotional, ethical and legal aspects. Consequently, the study of critical aspects which physicians take into consideration when they have to make their decisions is of a particular importance.

Commonly, the interest towards this field of research is growing due to the factors like the patients' need for information, involvement in treatment, consumer' interests and the general evolution in the nature of medical activities. This evolution in the relation between physicians and patients has been caused by a constantly growing illness duration as well as by its frequent acutization. The constant increase in chronic disorders and, in particular, of cancer, has generated a notable request of studies on this issue, and, since the physicians have to operate constantly in very complex and structured settings, the medical decision-making processes should be analyzed as well. On the other hand, the necessity to analyze through specific empirical studies the part which a patient plays is of increasing importance when, being an active part of the treatment flow, they have to choose between different therapeutic options which can cause positive or possibly negative effects on their life, as well as on the part of informal caregivers in assistance of terminally ill patients (Kaplan & Frosch, 2005).

The shared medical decision-making model is just one of the existing models and it can be found between paternalistic and informed models in related literature. In the shared decision-making model the power of control over the decision-making process is entirely entrusted to a patient. The interaction between patients, physicians and others (family members, for instance) is the starting point in the deliberation for the final decision-making (Gaston & Mitchell, 2005). So, a patient has to be well-informed on aetiology, symptoms, diagnostic methods, prognoses, advantages and eventual

risks of different treatments in order to evaluate together with a physician the possible alternatives of treatment in a conscientious and critical way. Thus, information is a crucial “power” for a patient (Shannon-Dorcy & Wolfe, 2003), i.e. it is an essential condition for so-called empowerment of a patient.

There’s an interesting branch of research considered to be a part of shared medical decision-making connected with an actual problem of end of life care, which is focused on study of medical decision-making processes in case of terminal illnesses, with particular attention to cancer disease care. The first observational study on end-of-life care medical decisions was performed in Italy in 2001-2003 by the *European End of Life Decisions (EURELD)* and involved general population level of research without being restricted to a particular field of medical care (intensive therapies, newborn cares or others). In this research there were involved the following European states: Italy, Switzerland, Belgium, Holland, Denmark and Sweden (Miccinesi, Fisher, Paci, Philipsen, Cartwright, van der Heide, *et al.*, 2005; Bilsen, Norup, Deliens, Miccinesi, van der Wal, Lofmark, *et al.*, 2006).

The obtained results show that in the European countries half of those persons who don’t die suddenly are assisted at their final phases of life with the intention of providing them with a tolerable quality of life rather than just simply prolonging their lives (Miccinesi, 2005). It has been observed, however, that there’s a big difference between Italy and the rest of the European countries examined. It means that the decisions taken by the Italian physicians are different by type and frequency of decisions from those made by their European colleagues. First of all, the medical decisions on end of life care in Italy are connected with minimization of suffering by intensification of therapy and, moreover, the decisions of non-treatment are taken about five times less in comparison with those taken in Holland, Switzerland, Belgium, Denmark and Sweden.

As for the Italian physicians, the focal point of the *Eureld’s* ethical discussion is the decision of non-treatment. On the other hand, 75% of the European physicians believe that the refusal of treatment from the side of a patient must be respected. In conclusion, only one half of the Italian participants in the research compared to at least 2/3<sup>rd</sup>’s of the other countries’ physicians do follow the above binding directives of non-treatment or vital therapy suspension. In order to understand the way of decision-making formulation by physicians, it is necessary to take into consideration how the part ascribed to a patient and relation between a physician and a patient may govern the decision-making in addition to the individual physician’s emotional state, their experience and professionalism. The vision of a patient considered to be competent is widely spread in the North America and at the North Europe, where a patient’s family assumes crucial position for decision-making process as well (Gaston & Mitchell, 2005). Nevertheless, the results emerged from a different studies show that there’s necessi-

ty of direct information in communication between a physician and a patient not only in Anglo-Saxon context (where the patients are usually informed on all important details), but also in South European context, where such a straightforwardness is generally considered to be more problematic (Varetto, 2004, Lucchiari, Pravettoni, Vago, & Boiardi, 2006; Lucchiari, Pravettoni, & Vago, 2008; Hubbard, Kidd, & Donaghy, 2008). Consequently, the medical system should be able to be attentive to patient's requirements and to satisfy their needs (Kaplan & Frosch, 2005). It means that medical practitioners have to be able not only to provide patients with professionalism, respect to beliefs and convictions, but also have to meet their needs into being involved into the treatment details and therapeutic choices.

A terminally ill person needs to be particularly involved with the medical staff and even receive a sense of empathy from them. In this context there may be an open, frank relationship obtained between physician and patient, thus any therapies or special treatments may assume their important significance even if these are just mere palliative responses. In this framework we conducted a survey on physicians' habitual kinds of approaches to decision-making in cases of care for terminally ill people, considering various parameters which, as mentioned before, can influence the relation between a physician and a patient and, consequently, the corresponding decision-making processes. The aim of this study was to describe medical decision-making processes on end of life cares of cancer diseases and analyze the possible factors which, as various sources report, might influence the decision-making style of medical staff in this context. Thus, we have tried to identify some theoretical parameters on physicians' approach to the shared decision-making model by means of a questionnaire prepared ad hoc for this study.

## 2. Materials and methods

The main tool used for this examination is presented by a questionnaire prepared ad hoc for this study and composed of twenty two items in a form of a multiple-choice test. The preparation of this test was based on information present in the Italian and the international contemporary literature on end of life care medical decision-making. The validity of its layout and contents had been prior analyzed by means of discussion with a panel of experts before its definite version was obtained. The questionnaire is divided into four areas of survey.

First area: patient's part in the medical decision-making. This area is supposed to find out the main characteristics and peculiarities in the relation between physicians and patients with special attention to patient's role in the treatment itinerary. The items have been organized in a way to learn the

physicians' attitude in evaluation of patients' decisional ability as well as the shared decision-making model advantages and disadvantages.

Second area: clinical decision variables. Here, the clinical and objective parameters used by physicians for therapeutic decision-making are examined using the items of this area.

Third area: subjective decisional variables. In this area, on the contrary, the non-clinical parameters which may influence more or less on a physicians' actions are analyzed. Are there any patient's features, apart from symptoms of a disease, which can influence the decision-making process?

Forth area: in this section, the influence by a family member (informal caregiver) on the therapy selection by a specialist is examined.

The set of options in the present test is represented by the four-level Likert scale (disagree, quite agree, agree, strongly agree). This questionnaire was distributed by email in the period between July and October 2008. The target of this study were the physicians dealing with terminally ill people with the medium range between six months and one year of foreseen survival from the date of final diagnoses. This target was selected from the staff of hospitals, research institutes, centers for palliative diseases, hospice all over Italy, as well from the specialists of different medical areas, like: oncology, pediatric oncology, surgical oncology, hematology, therapists of palliative diseases. As a summary, 650 e-mails were distributed and 102 valid replies were received thereafter. Respondents characteristics may be found in table 1.

Table 1 - *Respondents characteristics*

		<b>mean</b>	<b>sd</b>
age		44.32	6.3
		<b>n</b>	<b>%</b>
gender	men	60	59
	women	42	41
medical specialty	Oncology	77	75
	Pediatric Oncology	17	16
	Neurology/Neurosurgery	8	9

A descriptive analysis were conducted, considering level three and four of the Likert scale as complete positive response (agree) to an item. When particularly interesting trends were found, non parametric tests ( $\chi^2$  and Mann-Whitney test) where used to validate specific hypothesis.

### 3. Results

As a result of descriptive analysis performed with the use of questionnaires, the information emerged is useful to understand the decisional behavior of the physicians participated in this survey. Hereafter, its most significant items are divided by their areas of pertinence and then commented upon.

#### *First area: patient's part in the medical decision-making*

So, 68% of the physicians participated in this analysis consider that it is not correct to assume detached behavior towards the patient at the moment of diagnosis communication (item 4). Anyway, only a very small percentage of the physicians (11.5 %) declared themselves to be absolutely in agreement with this strategy. Though, 61.2% of the specialists do agree with an affirmation from the item 21 which asserts that sometimes a physician's emotional involvement in relation to a patient may be in ethical contrast to his scientific position. Thus, feedback to the above two statements seem to prove that even if there's an awareness about the importance of emphatic relations with a patient, at the same time there's some caution about consequences which such an emotive relationship can produce. It is clear that these considerations are not so easily manageable since the context of "end of life" implies anxiety, fear and anguish among patients, relatives and physicians.

Item 5 clearly shows that the majority (65%) do agree that a patient should be informed on their real conditions. A patient has a right to know the diagnosis and a physician has to communicate this fact. But, considering the possibilities of an ill person to stand and gain certain information, it is necessary, however, that the news about their real conditions be communicated gradually and with a certain sensibility. Until the Sixties it was commonly accepted that the fatal diagnosis should never be communicated to a patient. Nowadays the situation has changed as was confirmed by the results of our survey as well. Nevertheless, 78.2 % of the participants in this study do agree that there are some communicational problems between a physician and their patients (item 20). This fact was already mentioned in different sources of related literature. Our statistics just highlight the difficulties which physicians face in communication with their patients (and corresponding parents). So the physician, in order to establish a therapeutically valid relationship with a patient, has to try to formulate his messages in a clear and unequivocal form to avoid patient and relatives' anxiety. However, communication between a physician and a patient is complicated and implies facing significant obstacles (like the use of particular difficult to understand terminology; difficulties in the relationship established between a physician and patient; difficulties connected with the reality of the disease).

Item 14 examines the physicians' approach to a patient's request on interruption of therapeutic treatment. The participants in the survey were divided almost equally between the four options of answers present in the test. In Italy the delicate discussion on artificial life sustenance of terminally ill people in the final stage of their illness is still open, so the results obtained are more than realistic. Besides this, 69% of the specialists declare in favor of sustaining an attempt at survival prolongation by therapeutic means even if a patient requests anticipating the "natural" end of life (item 17). It is worth saying that 40% of the physicians declared to "quite agree" on this, since there's some ambiguity related to legal, clinical and moral aspects of the relation between a physician and patient, and the way the patient is considered. This was confirmed also by statistics on opiate substance use for pain control of cancer diseases at an advanced stage. So, 75% of the specialists declared to agree completely with the necessity of discussing with a patient the use of such substances or their upgrade, showing in this way their will to share the decision-making process with a patient in an active manner.

#### *Second area: clinical decision variables*

Item 1 is supposed to highlight the double nature of cancer disease in advanced stage ill person treatment. A physician treating terminally ill person knows very well about the impossibility to save their life, so his efforts should get them to improve the quality of the rest of patient's life. Only 14.3% of the practitioners declared to disagree with this statement.

Items 9 and 10 analyze physicians' opinion on the value of terminally ill people life quality. According to our studies, the life quality of a patient is considered to be an important point (82%) for a therapeutic decision-making process involving searching for a best solution, as well as life duration and age of a patient.

#### *Third area: subjective decisional variables*

Forty-one point four percent of participants agree to modify their decision from patient to patient taking into consideration, thus, not only their pathological characteristics but also the psychological (item 13). Items 7 and 8 try to examine physicians perception of patient's attitude during the curative relations. Ninetysix point six percent of specialists consider that patients try to assume an active position in the therapeutic process as soon as they come to know their diagnosis. Besides that, the specialists reveal that they find more active and involved patients under 40 as they try to participate in the therapeutic decision-making process.

In conclusion, the answers to item 12 show that 65% of physicians do agree on different approaches to younger patients (under 40), as they try to provide these patients with longer period of survival even if this may imply more aggressive and sophisticated therapies. As our survey shows, there's no any difference between women and men's reactions to their illness. The



survey participants do consider that there's almost no gender difference in therapeutic itinerary for patients.

*Forth area: informal caregiver's part*

Item 15 analyzes the physicians' approach to the terminally ill patients' family members. Forty-two point nine percent of specialists quite agree with the statement that terminally ill person's family members may decide on the treatment options instead of the patient itself (in case the conditions of an ill person make this necessary). At the same time, 25% of the specialists do disagree with the above statement, meanwhile, only 31.2% of the participants, contrarily, would give the whole responsibility of choice to family members. Thus, this item brings into discussion the informal caregivers' role in the treatment of patients terminally ill with cancer. Generally, in most of the cases, an informal caregiver corresponds to one of the close relatives (husband or wife, parents, children). In fact, the major part of support and assistance received by an ill person is provided by their family members. It is clear that, in such a context, the spirit of collaboration and trust should be established between medical staff and patient's family members. Our survey, however, confirms that very often this relationship is complicated and of a conflicting nature. This relation is complicated, in fact, because it is influenced by factors of a moral, clinical and legal nature which are not always easily analyzed.

This situation is highlighted by answers to items 18 and 19. Even if 90% of the specialists do agree completely with the statement that the family members (or, persons close to a patient) have to be involved in the decision-making process; item 19, however, shows a very different picture of reality. In fact, about 51% of physicians declare themselves not to be influenced on their decisions by patients' family members, while about 47% affirm an opposite position (only 2% of the specialists agree and others didn't answer on this item). It is clear that we are witnessing the representation of two different realities. So, we can suppose that this variable, in the context of our analysis, serves us to distinguish two different approaches, which we will define as sharing and non-sharing.

Hence, considering item 19 to be two-level fixed factor (agree/disagree) and analyzing the answers available by means of non-parametric significance tests for 2 independent samples (Mann-Whitney U), it became possible to identify the significant differences between these two approaches. In details, the specialists from "sharing" approach group declare to agree with the item 1 (palliative cares attitude;  $U = 414,50, p = .02$ ), with the item 3 (consideration of patients' needs;  $U = 448.00, p = .05$ ), with the item 13 (evaluation of patient's reaction;  $U = 402.00, p = .01$ ), with the item 18 (family members' involvement;  $U = 404.50, p = .01$ ), with the item 20 (communicational problems perception;  $U = 436.25, p = .05$ ) and with the item 21 (physician's emotive involvement;  $U = 398.50, p = .01$ ).

Effectively, the two approaches differ neatly one from the another in correspondence with role of physician, patient and patient's family members. The specialists from the "non-sharing" group declare themselves to be emotively detached and have some kind of "paternalistic" decision-making style, where the participation of patients and their family members, being important in any case, is considered useful for comparison and not as a point for orientation. Besides this, the physicians from this group seem to pay less attention to the problem of communication between a physician and a patient, so they report it with less conflict, more easily manageable. It is curious to point out that the "sharing" group is composed mainly of female physicians, who show particularly high scores (i.e., they do *absolutely agree*) for the items 1, 3 and 21 (table 2).

Table 2 - Gender difference between "sharing" and "non-sharing" group (*chi-square = 7.19, p < .05*)

		Gender		
		Males	Females	Total
Group	Non-sharing	39	16	55
	Sharing	21	26	47
Total		60	42	102

As the results of our survey show, female physicians are generally more attentive to the patients' needs (item 1), besides that, the results confirm that they seem to be more aware of interdependence between emotional involvement and decision-making styles (item 21). Never the less, the male specialists declare to be more attentive to the patient's will in their decision-making process (item 3). But this doesn't mean major human sensibility towards the patients, but merely that the male doctors seem to be more open to accept a patient's point of view and competences as an active participant in therapeutic decision-making itinerary.

#### 4. Discussion

The present survey clearly shows, that the medical decision-making process on terminally ill people care represents a very complex reality and

is subject to the influence of a medical, ethical, social and cultural character, which may result in even very different approaches to these problems from physician to physician. Nowadays, due to technology improvement in research and approaches to varying treatments of diseases, a physician becomes the recipient and “carrier” of very complex scientific knowledge much more than in the past. This progress implies a huge responsibility in medical decisions, and these responsibilities require a constantly present, particular attention in terms of management and research in order to provide patients with therapy which meets their needs and supports a physician in the execution of his difficult job.

The present study on medical decision-making processes on end of life care has brought to light some interesting points. First of all, the importance of the relation between a physician and a patient has emerged. This relation consists of the following set of elements: the patient playing a double role of a personality on one side and of the ill person on the other who needs an assistance the physician with his professionalism and personal characteristics, and the context where their relation takes place. In this relation between physician and terminally ill patient, the patient is subject to the physician’s actions. This emotive and affective interdependence should be considered in the medical practice analysis. The relation between a patient and a physician is influenced by different elements from the sides of both parties. At this point, it is very difficult to identify the way these personal elements influence the treatment process. There were two research projects conducted in Italy on this issue, first one first performed by Marasso *et al.* on 1988 (Marasso, Cianfruglia, Crotti, De Falco, & Tamburini, 1988) and the other one by Tamburini and colleagues on 1988 (Tamburini, Gamba, & Marasso, 1988), and it was revealed that the physicians’ behavior and relation to a patient differs from one medical category to another.

In the second place, there’s an importance of communication in terms of therapy (i.e., that a patient has a right to know the diagnosis and a physician has to communicate it to him). This information should be communicated according to the ability of a patient to understand and work out the information received. Every ill person has their unique features and character, so it is not absolutely possible to apply the same “ready-made” relational method to all patients or their families. The form, quantity and sort of information to be communicated to a patient should be defined by a physician each time according to the patient and his characteristics. With the help of a personalized approach, it is possible to let a patient decide on the quality and quantity of information he needs for better understanding the therapeutic situation. This method assures better sharing of difficult therapeutic decisions to be taken between a physician and patient. Taking into consideration the subjective parameters allows a physician to center his attention first of all on a fundamental parameter of life quality along with its duration and, more generally, to control the symptoms (the objectivity). Our

survey has examined the subject of communication as well. The communication between a physician and a patient may lead to development of a therapeutic relationship based on trust and sharing of specific therapeutic targets. Our data shows that the specialists participated in the survey are aware of this fact and there's also a significant difference between their targets in this communication. Besides this, many of them affirm facing problems in such a difficult communication with patients and their family members. Thus, it is very important to support a physician on this issue. During the last ten years Italian physicians have become always more disposed to inform their patients on the malignant character of their disease (Costantini, 2001). Considering results of some surveys conducted on Eighties, like one of Costantini and his colleagues (Costantini, De Marinis, & Nosedà, 1992), which clearly showed that from 80 families of people with lung cancer on advanced stage, 82% of patients was not informed on their diagnosis (Costantini *et al.*, 1992), we can affirm that the improvement in the last years on this issue is of great importance. One of the following surveys performed by Ruggeri showed that only one half of 2088 examined patients with advanced stage of cancer disease had even a remote feeling about their real diagnosis (Ruggeri & Cortesi, 1999). Consequently, it is a big importance to provide the medical staff with training on communicational skills. For example, Kaplan (Kaplan, 1996) proved with the help of his survey on more than 7.000 patients and 300 physicians, that the medical staff with communicational studies background involves more frequently their patients into the decision-making process, and, consequently, there's the highest level of satisfaction among these physicians and their patients. But, in oncology the problem of communication is more sophisticated due to the emotional factor that affects patients, their family members and physicians. Surely, the taboos associated with the cancer and, especially, with death make it difficult to talk about. Very often communication in oncology is characterized by silence and divergence between medical staff and patients' family members (Tomamichel, 1999), as the results of our survey seem to prove it as well. In fact, the specialists participated in the survey seem to understand the difficulties of relations between physician and patient with consequent problems of treatment quality from one side and professional satisfaction of the practitioner from another. Nevertheless, it seems like there's the necessity, at least for one group of the examined specialists, to simplify the above situation with the help of decisional styles, which can avoid the patients' subjective parameters in order to reduce the ambiguity and uncertainty related with legal and moral aspects that may turn to be difficult to solve.

The third important point emerged from this survey is the perception of life quality value. The major part of the questioned specialists agree on the high importance of their patients' life quality. Making therapeutic decisions based on life quality means to intensify the symptoms' control, which, in

some cases, may be a request to anticipate life's final termination, or, at least, it means not to consider the patients' survival to be an irrevocable target. This may lead to alteration of clinic decision-making models in case of terminal cancer diseases. This fact was proved by different national and international studies on this issue (Danti, Sirigatti, Gabbrielli, & Cavallini, 2006). In details, it becomes very complicated to manage the relation between quality of life and its duration considering personal features of different patients. It means, as statistics show, that there's a different approach to survival duration in case of younger patients. Probably, because they show themselves to be more active, to be more culturally enriched, and are more prepared to ask questions regarding the therapeutic choices and attempts to evaluate their treatment options, while elderly people or people with a less-strong cultural background trust the physicians more and let them make the therapeutic choices.

The fourth and the last significant point examines caregivers' importance in assistance of terminally ill people. Patients' family members greatly influence the physician's decision-making process. This may be explained by the fact that an ill person receives major support and assistance from their family members. Usually, as the survey conducted by Palliative Care Italian Observatory showed, a caregiver is identified with a woman (patient's family member) who takes care of all needs and requirements of a patient (Corli, Pizzuto, Nastri, & Marini, 2005). Physicians agree on the informal caregivers' importance, but still, as the results of our survey show, they are not considered so much either for the establishment of relations with a patient nor for important medical decision-making. In addition, a not always positive and easy relationship can be established between medical staff and patients' family members. Consequently, it appears that the improvement of relations between medical staff and patients' family members is required not only to provide a patient with better support but also to guarantee an optimal treatment quality from the side of the medical staff.

In conclusion, we would like to point out that from our survey there emerged some important issues related to the palliative care context. Nowadays, this context is subject to a very dynamic evolution determined by medical progress and conditions of a cultural and social nature like the evolution of relations between physician and patient (patient's emancipation) as well as the evolution of social representation, always less idealized and more problematic, of physicians. Besides this, there's a moral question within the domain of palliative care, which is strictly related with the biological testament issue, which can't be solved with or without the help of an operational unit organization and turns-out to be very critical for the experience and decision-making process of a physician.

The specialists participating in the survey have highlighted the physicians' role in the context of decision-making at the end of life situations as very problematic and complex. Still, the approach to the sharing deci-

sion-making among the specialists doesn't prove to be that homogeneous. As mentioned before, this model is considered to be an ideal, to which an application in real situations doesn't always correspond. There are, actually, a lot of problems related to this argument, and, sometimes, it turns-out to be much easier to apply a more directive decisional style, which may be considered to be the best one. In conclusion, the data related to the gender differences of the shared decision-making approach was very interesting, i.e., the male specialists are more overt than female specialists, who declare themselves to be more attentive to a patient's needs but less interested in getting involved in the decision-making process.

The results of our survey, though partial and limited due to exiguity of participants, suggest that there's the necessity to discuss the matter of medical shared decision-making more thoroughly in order to involve patients with relative family members into the treatment decision-making process, and provide physicians with support in the management of problematic areas like communication and control of emotions.

## References

- Annunziata, M. A. (1997). Il medico e la morte: opinioni e comportamenti di 605 medici della provincia di Pordenone. *Quaderni di Cure Palliative*, 2, 84-90.
- Bilsen, J., Norup, M., Deliens, L., Miccinesi, G., Van der Wal, G., Lofmark, R., Faisst, K., & Van der Heide, A. (2006). On behalf of the Eureld consortium. Drugs used to alleviate symptoms with life shortening as possible side effect: end-of-life care in six European countries. *Journal of Pain and Symptom Management*, 31, 111-121.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared Decision-making in the medical encounter: what does it mean? (or It takes at least two to Tango). *Social Science Medicine*, 5, 681-692.
- Corli, O., Marini, M. G., Natri, A., & Pizzuto, M. (2005). *La famiglia e il malato terminale Analisi di problemi, difficoltà e soluzioni relativi alle famiglie che accudiscono un malato in fase avanzata di malattia inguaribile. Progetto indagine OICP 2004*. Centro Studi e Ricerche Osservatorio Italiano Cure Palliative.
- Costantini, A. (2001). La comunicazione della prognosi. *Giornale di Psico-Oncologia*, 3, 42-45.
- Costantini, A., De Marinis, F., & Nosedà, M. A. (1992). La famiglia del paziente con cancro polmonare: indagine preliminare all'istituzione di un servizio di assistenza domiciliare. *Annals of Institute Carlo Forlanini*, 12, 276-282.

- Danti, S., Sirigatti, S., Gabbrielli, A., & Cavallini, V. (2006). Qualità della vita e previsione di sopravvivenza in un gruppo di malati oncologici terminali. *La Rivista Italiana di Cure Palliative*, 2, 10-16.
- Gaston, C. M., & Mitchell, G. (2005). Information giving and decision-making in patients with advanced cancer: a system review. *Social Science Medicine*, 61, 2252-2264.
- Hubbard, G., Kidd, L., & Donaghy, E. (2008). Preferences for involvement in treatment decision making of patients with cancer: A review of the literature. *European Journal of Oncology Nursing*, 12, 299-318.
- Kaplan, S. (1996). Characteristics of physicians with participatory decision making styles. *Annals of Internal Medicine*, 2 (3), 128-145.
- Kaplan, R. M., & Frosch, D. L. (2005). Decision Making in Medicine and Health Care. *Annual Reviews Clinical Psychology*, 1, 526-549.
- Lucchiari, C., Pravettoni, G., Vago, G., & Boiardi, A. (2006). *Quality of life and shared decisions in patients with high grade gliomas*. The 28th Annual Meeting of the Society for Medical Decision Making. Boston, Usa.
- Lucchiari, C., Pravettoni, G., & Vago, G. (2008). *To Share or not to Share: Physicians and Patients Approaching the Clinical Uncertainty*. HEPS conference, Strasbourg.
- Marasso, G., Cianfruglia, F., Crotti, N., De Falco, F., & Tamburini, M. (1988). Physicians attitudes in the management of terminally ill patients, a safer death, multidisciplinary aspects of terminal care. In A. Gilmore and S. Gilmore (eds), *A Safer Death: Multidisciplinary Aspects of Terminal Care* (pp. 191-204). New York: Plenum Publishing Corporation.
- Miccinesi, G. (2005). Decisioni di fine vita: le opinioni dei medici. *Occhio Clinico*, 1, 35-46.
- Miccinesi, G., Fischer, S., Paci, E., Onwuteaka-Philipsen, B. D., Cartwright, C., van der Heide, A., Nilstun, T., Norup, M., & Mortier, F. (2005). Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. *Social Science and Medicine*, 60 (9), 1961-1974.
- Ruggeri, B., & Cortesi, E. (1999). Awareness of disease among Italian cancer patients: is there a need for further improvement in patient information? The Italian Group for the Evaluation of Outcome in Oncology (IGEO). *Annals of Oncology*, 10, 1095-100.
- Shannon-Dorcy, K., & Wolfe, V. (2003). Decision making in the Diagnosis and treatment of leukaemia. *Seminars in Oncology Nursing*, 2, 142-149.
- Tamburini, M., Gamba, A., & Marasso, G. (1988). Comunicazione della diagnosi di cancro e terapie dei malati in fase terminale. *Federazione Medica*, XLI, 6.

Tomamichel, M. (1999). Un modello individualizzato per migliorare la comunicazione in oncologia. *Giornale Italiano di Psico-Oncologia*, 1, 11-15.

Varetto, A. (2004). La comunicazione medico-paziente. In C. Benedetto, M. Massobrio (eds), *Psicosomatica in ginecologia e ostetricia. Una medicina a misura di donna*. (pp. 117-118). Roma: CIC Edizioni Internazionali.



## Mental retardation and reading rate: effects of precision teaching

*Francesca Cavallini,<sup>1</sup> Federica Berardo<sup>2</sup> & Silvia Perini<sup>3</sup>*

### Abstract

*This study evaluates the effectiveness of a brief intervention programme (word recognition) aimed at increasing the reading rates of two pupils with mental retardation. The program used frequency-building procedures aimed at increasing reading rates for either common words, the programme used Precision Teaching to monitor intervention effectiveness. Results showed that the two word recognition training participants made significant gains in overall reading skills. This study provides additional evidence for the effectiveness of Precision Teaching and frequency-building procedures, and word recognition as well as support for the idea that successful reading interventions need not require time-consuming resources.*

**Keywords:** Precision Teaching, Words, Fluency, Retardation, Reading

*\* Received: 17 December 2009, Revised: 13 April 2010, Accepted: 10 May 2010.*

<sup>1</sup> Faculty of Psychology, University of Parma, Borgo Carissimi, 10, 43100 Parma. E-mail: francesca.cavallini@unipr.it

<sup>2</sup> University of Parma. E-mail: federica.berardo@nemo.unipr.it

<sup>3</sup> University of Parma. E-mail: silvia.perini@unipr.it

## 1. Introduction

Significant research advances have been made in recent years in the area of mental retardation (Perini & Bijou, 1993; Iwata, Bailey, Neef, Wacker, Repp, & Shook, 1997; Greer & Ross, 2007). Unfortunately, educational programs and teaching strategies have remained virtually untouched by these findings. There is still a general tendency to emphasize the development of physical and social skills, in the belief that children with mental retardation have very little potential for cognitive development. An incredible number of stereotyped clichés have grown up around this socially excluded group we call the “retarded” that they are “slow learners” needing slow teaching. In particular currently available curricula, do not take into account levels of learning such as fluency (Heward, 2003a, 2003b; Kubina, 2005). We propose that fluency increases the functionality of skills for students with mental retardation and should be systematically programmed into a curriculum. In general, the term fluency has entered into the vernacular for most people. When asking someone to provide synonyms for fluency (e.g., to describe a fluent speaker, dancer, or writer), words such as smooth, flowing, accurate, graceful, automatic, and effortless may be given.

How can teachers best provide fluency instruction for their students with mental retardation? One answer lies in a technique called Precision Teaching. Developed by Ogden Lindsley in the 1960s, Precision Teaching procedures have consistently demonstrated great potential for strengthening any school curriculum (Beck & Clement, 1991; Lindsley, 1992) and with children with mental retardation (Fabrizio, Pahl, & Moors, 2002; Cavallini, Berardo, & Perini, 2008) is a general approach that can help a teacher to determine whether their teaching is having the desired effects on learning. The concept of PT, rests on four founding principles: “(1) the child knows best: in the sense that a child’s response to a task or learning approach is the best indicator of whether a given teaching method is working with that child; (2) Focus on observable behaviours: a practical rule that makes it possible to take accurate counts, to monitor whether a child is improving in response to the current teaching method; (3) Use frequency measures to monitor performance: PT focuses on rate, or frequency of responding, which can only be measured by using the number (or count) of correct and incorrect responses within a given timeframe; and (4) Use a standardised graphic display, standard celeration chart, to record performance measures and make instructional decisions” (Hughes, Beverley, & Whitehead, 2007, p. 2). The four principles have been described in greater detail in several publications (West, Young, & Spooner, 1990; White & Neely, 2004; Calkin, 2005).

Research shows that Precision Teaching can facilitate growth in reading fluency and other aspects of reading achievement (Adams, 1990; Therrien, 2004) also for children with mental retardation (Sulgrove, & McLaughlin, 2004; Cavallini *et al.*, 2008). A solid foundation for reading is created by sys-

tematically establishing the basic components of reading and then bringing those skills to fluent levels. In fact, if component skills are not fluent, moving on to tasks predicated on those skills makes learning more difficult and may ultimately lead to dysfluency in that subject (Kubina, Young, & Kilwein, 2004).

Reviews of the Italian reading literature for typically developed children (Tressoldi, Vio, Lorusso, Facoetti, & Iozzino, 2003; Riccardi Ripamonti, Truzoli, & Salvatico, 2004; Cazzaniga, Re, Cornoldi, Poli, & Tressoldi, 2005) and for children with mental retardation (Fedeli & Meazzini, 2004; Cavallini *et al.*, 2008) point to two behaviours that most likely function as foundational skills for reading: syllable recognition and word recognition. The general notion is that if students are fluent in decoding skills, they will spend “less time and effort... directed to recognition activities” (Gunderson, 1984, p. 267). The correlation between fluency and reading comprehension was clearly established by a large-scale analysis of data from the National Assessment of Educational Progress in Reading (Pinnell, Pikulski, Wixson, Campbell, Gough, & Beatty, 1995). Reading fluency refers to rapid, efficient, accurate word recognition skills that permit a reader to construct the meaning of text. Fluency is also manifested in accurate, rapid, expressive oral reading and is applied during, and makes possible, silent reading comprehension. Precision Teaching represents an educational strategy for building reading fluency in which a student rereads words or syllables until meeting a criterion level (Cavallini *et al.*, 2008). Cavallini and Perini (2009), found that, in typically developed children, promotion of sublexical component fluency does not show evidence of influencing reading as a general performance. Conversely, the automatization of word recognition positively affected text reading. The current study evaluate the efficacy and efficiency (in term of educational time) of teaching frequent words to fluent levels in 2 children with mental retardation.

## 2. Method

### 2.1 Participants

Two children participated: Mara was 8 years old girl with Down Syndrome, she had a mental age equivalent score of 4 years 9 month on the WISC-R (Wechsler, 1974) and was enrolled in an elementary school, Nicolò was 8 years old, with mental retardation due to cerebral palsy, he had a mental age equivalent of 5 years 2 months on the WISC-R (and was enrolled in an elementary school in San Damiano (PV)). Both participants could name all of the Italian-language letters and syllables.

The children's parents gave informed consent for their children's participation in the study. Each child was assigned a teacher-researcher who

worked daily with the child, and a supervisor who evaluated the pupils' progress once a week.

The research setting was a room at the Tice Learning Centre, a learning center near Piacenza, presenting a unidirectional mirror, a desk, and two chairs.

### *2.2 Stimuli and apparatus*

During the experimental phase a digital timer was used for practice sprints. The children's performance data were entered on a standard celeration chart and on a registration sheet. Specifically, the participants' best trial performances were recorded on the single subtask standard celeration charts, but the children's mean score for three age-graded reading scores (see below) was registered on a specific, age-graded-text reading standard celeration chart. A data collection sheet was used to guide the teaching. The data collection sheet, contained the teacher indications concerning appropriate instructions, correction procedures, etc., was used to define curricula (see below), trial number, trial duration, and errors (including instructions on how give the pupils feedback on them).

### *2.3 Instructional and testing materials*

Curriculum: the material used for the experimental phase, the word-fluency programme, was a "curriculum" developed by the Tice Learning Center (Cavallini, Andolfi, Berardo, & Pignoli, in press). The curriculum lists the 1,000 most frequent words in the Italian lexicon (Marconi, Ott, Pesenti, Ratti, & Tavella, 1994) subdivided by length (from 3 to 12 letters). Specifically, the curriculum contains 35 three-letter words, 104 four-letter words, 184 five-letter words, 202 six-letter words, 180 seven-letter words, 139 eight-letter words, 71 nine-letter words, 64 ten-letter words, and 21 eleven- and twelve-letter words. The words are presented on worksheets listing 10 (same-length) words on each, which are randomly ordered into 10 x 10 tables.

### *2.4 Measures*

The study used a single-participant experimental design in which the two pupils receiving were monitored throughout the programme in terms of number of words correctly read per minute and numbers of learning opportunities; a multiple baseline across participants was used to evaluate the effectiveness of the training. This design addresses the impact of the treatment of the independent variable on the dependent variable, the same behavior, for different participants. Once a baseline has been established, the treatment or independent variable was applied to one of the participants. During this time, baseline was maintained for the other participants. Once improvement is seen for the first participant, the treatment is started with the second subject.

Tests were conducted before, during and following the intervention for the two participants before, during, and at the end of training, to analyse the effects of training on age-graded text reading speed. The tests were conducted according to procedures (Curriculum Based Measurement; Deno, 1985); that is, conducted by presenting the participants with three different texts, in different times, selected from a reading series written for third-form children (third-grade reading level).

### *2.5 Procedure*

The two children participated in two 40-minute sessions per week, for a period of approximately 5 months. During the training period, the participants conducted brief practice sprints (duration approximately 10 seconds) aimed at increasing fluency in frequent word recognition. The two pupils participated each session in 18 sprints (range 12-20 secs.); that is, two sprints per worksheet (3, 4, 5, 6, 7, 8, 9, 10, 11 letter words).

Each child worked with a single teacher-researcher in a Tice Centre training room, while another researcher observed the session through the two-way mirror and verified the validity of the teacher-researcher's recordings. Before beginning the worksheet sprints, the children were informed of the fluency aims relative to each series of words, and the experimenter prompted each child to do his/her best on each trial (e.g., "Come on; you can beat the record!"; "Now, try to be as fast as lightning!"). The conditions for receiving positive reinforcement were explained to the children (a token was given each time they beat their own record); their attention was drawn thereby to the idea of "competing with, and outdoing" themselves. Indeed, these are examples of some specific aspects of Precision Teaching that help children focus on their own learning progress (considered as a positive difference in successive performances) and on their own improvement. The children were instructed to read as fast as possible, to skip words that were too difficult, and to continue working until the timer sounded. In line with Precision Teaching procedures, the number of words presented per page in a given session was higher than the number of words that each participant could have managed to read in that session. Each child read the words from right to left and went through the two or three practice sprints for each group of words, as described above (At the end of each sprint, the word list was substituted by a different version that had the same words, but in a different order).

Fluency aims were determined by using White's (1985) procedure; that is, by taking the average score of 6 competent peers (7 years old) carrying out the same task. A frequency range comprising 60 and 100 words per minute was chosen for words.

When children made errors during the sprints, the experimenters wrote the word on a flashcard. At the end of the sprints, and after having given the pupils feedback on their performance, the teacher-researchers helped the

pupils read the error flashcards (word/syllable). The children were prompted to sound the error word out (e.g., “okay, this card says az-zur-ro [light-blue]; now you try”) then, the experimenters marked down the highest score for the three word drills on the children’s standard celeration chart, showed them their progress, and commented on the results. To evaluate the efficacy of training with respect to speed improvement in age-graded text reading (i.e., observed in composite skills after practicing component skills and defined as “application”; Kubina *et al.*, 2004; Hughes, Beverley, & Whitehead *et al.*, 2007; Cavallini & Perini, 2009), the participants were presented with three different texts per week, and specifically, the CBM tests taken from a book series written for 6- to 7-year-old children. During evaluation, the texts were presented to the children without illustrations, on an A4-size sheet of paper; the teacher-experimenters worked with a copy of the same page, upon which they marked the child’s reading errors. The children read each of the three texts aloud for one minute and, upon conclusion of the three trials, the experimenters recorded each child’s mean error- and correct syllables score calculated by adding the number of correct or wrong syllables and dividing them by 3 on his standard celeration chart. The children were not corrected or given feedback on their performance during these tests. The first test was administered one month before training had begun; the final trial was conducted one month upon conclusion of the training programme; and the experimental-phase CMB tests were administered each week until the end of the school (for a total of 20 trials), because both of the children were supposed to leave after the end of the school.

### 3. Results

The children’s individual results for the component skill (words) were registered on their standard celeration charts; the participants had 9 standard celeration charts (one for each set of different word lengths). Figure 1 shows a typical example of standard celeration charts relative to 3-letter-word reading. Standard celeration charts were used for the dual purposes of monitoring pupil progress and making immediate learning decisions (White, 1985). Table 1 lists the two participants’ first- and last- session results for the single word sets.

Figure 1 - Example of Standard Celeration Chart for 3-letter word reading (Participant 1)

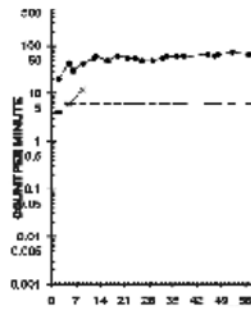


Table 1 - Correct rate scores at first and last session on different length words (from 3 to 11), the number of practice sprints and the total active time (seconds)

Letters for word	PARTICIPANT 1				PARTICIPANT 2			
	FIRST SESSION	LAST SESSION	NUMBER PRACTICE SPRINT	TOTAL ACTIVE TIME: seconds	FIRST SESSION	LAST SESSION	NUMBER PRACTICE SPRINT	TOTAL ACTIVE TIME: seconds
3	7	19	80	800	6	19	48	480
4	8	20	82	820	9	18	50	500
5	7	15	92	920	5	13	48	480
6	7	16	90	900	6	15	52	520
7	5	15	110	1100	4	13	64	640
8	6	16	108	1080	3	10	71	710
9	4	12	108	1080	4	9	70	700
10	4	10	110	1100	2	6	64	640
11	2	11	110	1100	3	8	70	700
Total			890	8900			537	5370

### 3.1 Age-graded text reading

The frequency of age-graded text reading (expressed as the number of correct syllables per minute) increased for the participant 1 during the word-fluency program phase but remain at the same level for the other child (participant 2), until she began the program and her reading frequency jumped up. Table 1 summarises each participant's training duration, initial frequency, and final frequency. Figure 2 shows the trend on the age-graded text reading frequencies obtained by the two participants at the beginning, midway through, and at the end of the study.

Figure 2 - Pre-post test difference expressed in terms of syllables per minute in age-graded text reading for the study's two participants. The Y-axis indicates frequency (count per minute) on an interval scale ranging from 0 per minute to 70 per minute. For each participant the fluency scores (correct and errors) for the start rate, the end rate

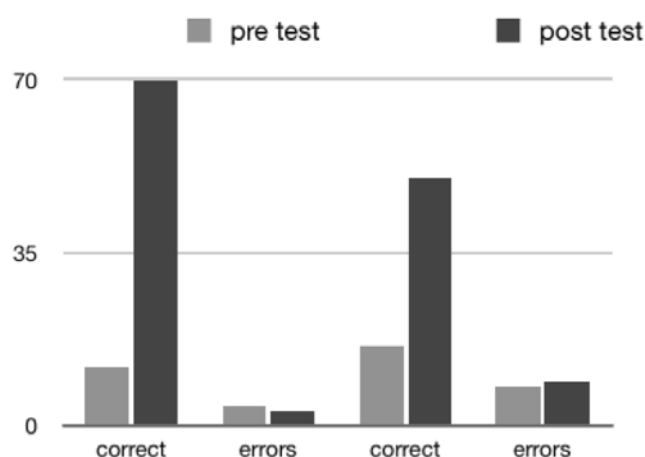


Table 2 - Training duration, initial frequency, and final frequency of age-graded text reading (expressed as the number of correct syllables per minute)

Participant	Total time	Pre-test correct	Post-test correct	Pre-test errors	Post-test errors
1	148 min	12	70	8	4
2	89 min	16	50	9	3

### 3.1 Age-graded text reading

The frequency of age-graded text reading (expressed as the number of correct syllables per minute) increased for the participant 1 during the word-fluency program phase but remain at the same level for the other child (participant 2), until she began the program and her reading frequency jumped up. Table 2 summarises each participant's training duration, initial frequency, and final frequency. Figure 2 shows the trend on the age-graded text reading frequencies obtained by the two participants at the beginning, midway through, and at the end of the study.



The C test (Caracciolo, Larcan, & Cammà, 1986) is a statistical test allowing for verification of the significance of the efficacy of an intervention. The table 3 summarises the C- and Z-scores relative to the data obtained by the two participants in the text reading trials. The scores obtained with the C-statistic, were transformed into Z-scores and then used to verify the significance indices for each participant series obtained in the text reading trials. Figure 3 shows each participant's progress in age-graded reading (composite ability). It is evident that, although reading frequencies increased significantly for the child who had received word-fluency program, the other child had no significant effects on text reading before the beginning of the training. As you can see from the graph, the frequency of learning opportunities (errors) do not significantly decrease for the two children during the intervention.

Figure 3 - Best score pairs for participants on CBM probes, expressed in terms of number of correct syllables per minute. The Y-axis indicates frequency (count per minute) on an interval scale ranging from 0 per minute to 70 syllables per minute, the X-axis represents practice sessions

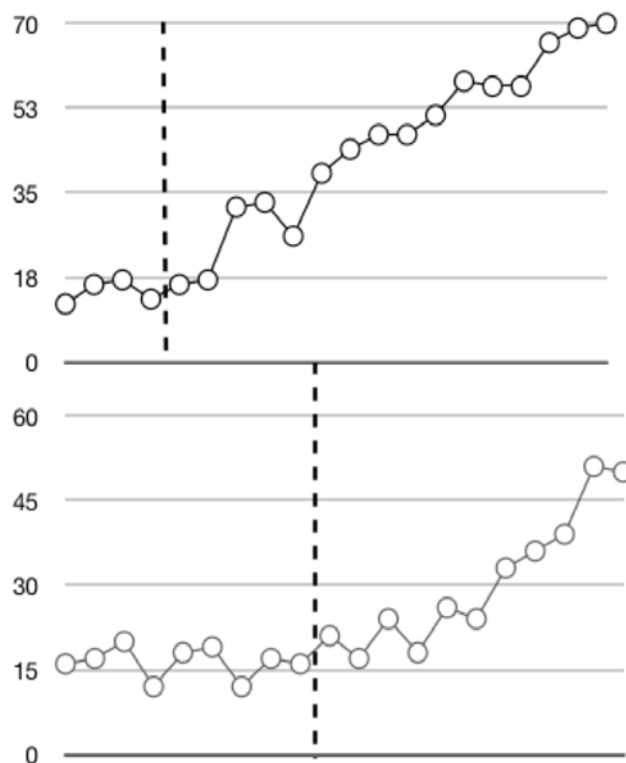
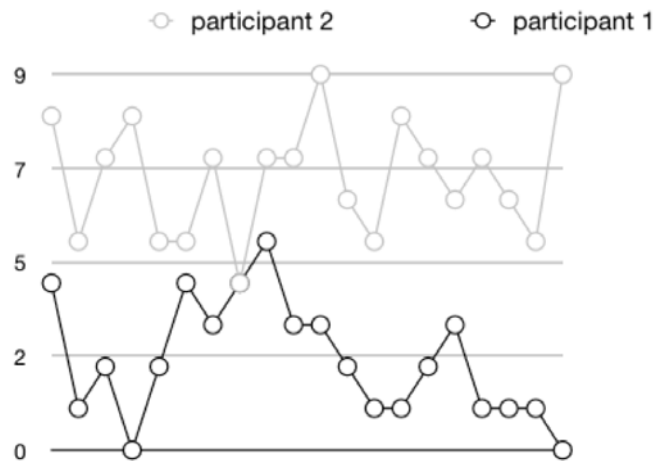


Table 3 - *C and Z-scores relative to the data obtained by the two participants in the text reading trials*

Participant	C	sc	Z	p
1	.929	.234	3.964	.01
2	.851	.284	2.796	.001

Figure 4 - *Best score pairs for participants on CBM probes, expressed in terms of number of incorrect syllables per minute. The Y-axis indicates frequency (count per minute) on an interval scale ranging from 0 per minute to 9 syllables per minute, the X-axis represents practice sessions*



### 3.2 Intervention duration

Each participant's Precision Teaching programme duration was calculated by summing the times (in minutes) during which the participants were actively involved in practice sprints. The mean was 89.5 minutes (range 99-80), subdivided into 10-second drills (range 594 - 480 total drills).

## 4. Discussion

One of the aims of the present study was to evaluate the extent to which fluency training in the component elements of reading would promote

greater improvement in age-graded text reading, an ability considered by Precision Teachers to be a composite skill (Kubina *et al.*, 2004; Cavallini & Perini, 2009) in two children with mental retardation. Despite the present study's limitations (small number of participants, no control), the data gathered and the results obtained lend themselves to a timely and interesting discussion. In our study, not only did the participants who became 'automatic' in reading frequent word recognition improve in the single curricula, they also developed a significant difference between their pre- and post-test scores (approximately 45 syllables per minute) as well as a significant improvement trend during the experimental phase ( $C=.929$  for participant 1 and  $C=.851$  for participant 2): in both applications, the series obtained is verified with the C statistic, the result is statistically significant and the presence of a trend change is inferred (DeCarlo & Tryon, 1993). The second consideration concerns the participants' errors: despite improvement in world reading frequency, the two children showed no significant improvement in accuracy, expressed either as a pre- to post-test difference or in terms of a significant trend observed during the treatment phase (as evaluated by the C-test). It seems that the training is very useful in increasing correct words reading frequency but we need other intervention to build accuracy. In general, results are in line with studies conducted with typically developed slow readers of English (Hughes *et al.*, 2007) and Italian (Cavallini & Perini, 2009) and appear to be of marked interest for children with mental retardation. Conversely, the automatization of word recognition positively affected text reading. A closer examination of this observed effect reveals the efficacy of Precision Teaching methodology, both as a clinical effect (an improvement, on average, of 45 syllables per minute) and in terms of intervention duration: in little more than an hour and half of practice, the two participants showed improvement that went beyond that typically achieved by normal readers in an entire school year of normal children. If we consider the effects correlated with an increase in reading speed, such as text comprehension (Fuchs & Fuchs, 1986; Nathan & Stanovich, 1991; Therrien, 2004), it appears evident that Precision Teaching used in association with a word-recognition curriculum can represent an effective intervention instrument for teachers and educators. The use of brief practice sprints, constant monitoring of results, and the promotion of a sense of fun during repetitive practice (sprints) offers a new effective way to exercise many instrumental abilities that are typically considered to be "boring", but are crucial to achieving academic goals for children with mental retardation. As we discuss in the introduction a related piece of wisdom goes like this: students with disabilities can learn, but they learn more slowly; therefore, they should be given extra time and instruction should be given at a slower pace. Although this reasoning possesses a degree of logic and common sense, research has found that slowing the pace of instruction makes things worse, not better, for students with mental retardation

(Heward, 2003a, 2003b). For example, Carnine (1976) conducted an experiment in which instruction was presented to four first-grade remedial reading students at two paces: slow (interval 5 seconds) and fast (interval 1 second). Fast-paced instruction resulted in more learning trials presented by the teacher, more responses per lesson by the students, better accuracy of students' responses, and better on-task behavior. Systematic replication of this study yielded a similar pattern of results (e.g. Carnine & Fink, 1978; Koegel, Dunlap, & Dyer, 1980; Darch & Gersten, 1985; Williams, 1993).

## References

- Adams, M. J. (1990). *Beginning to read: Thinking and learning about print*. Cambridge, MA: MIT Press.
- Beck, R., & Clement, R. (1991). The Great Falls Precision Teaching project: An historical examination. *Journal of Precision Teaching*, 8 (2), 8-12.
- Calkin, A. B. (2005). Precision Teaching: the standard celeration charts. *The Behavior Analyst Today*, 6, 207-213.
- Caracciolo, E., Larcana, R., & Cammà, M. (1986). Il test "C": un modello statistico per l'analisi clinica e sperimentale di serie di dati in serie temporali relativi ad un partecipante singolo (N=1). *Bollettino di Psicologia Applicata*, 175, 43-54.
- Carnine, D. (1976). Effects of two teacher presentation rates on off-task behavior, answering correctly, and participation. *Journal of Applied Behavior Analysis*, 9, 199-206.
- Carnine, D., & Fink, W. T. (1978). Increasing the rate of presentation and use of signals in elementary classroom teacher. *Journal of Applied Behavior Analysis*, 9, 199-206.
- Cavallini, F., & Perini, S. (2009). Syllables or words? Comparison of teaching syllables or words on reading rate. *European Journal of Behavior Analysis*, 10 (2), 255-263.
- Cavallini, F., Andolfi, S., Berardo, F., & Pignoli, L. (in press). *Precision Reading*. Piacenza: Tice.
- Cavallini, F., Berardo, F., & Perini, S. (2008). Fluenza: un diritto e un dovere. Applicazione del Precision Teaching nell'insegnamento della lettura a una bambina con autismo. *American Journal on Mental Retardation*, 6 (2), 393-409.
- Cazzaniga, S., Re, A. M., Cornoldi, C., Poli, S., & Tressoldi P. E. (2005). *Dislessia e trattamento sublessicale*. Trento: Erickson.
- Darch, C., & Gersten, R. (1985). The effects of teacher presentation rate and praise on LD students' oral reading performance. *British Journal of Psychology*, 55, 295-303.
- DeCarlo, L. T., & Tryon, W. W. (1993). Estimating and testing autocorrelation with small samples: A comparison of the C-statistic to a modified estimator. *Behaviour Research and Therapy*, 31, 781-788.
- Deno, S. L. (1985). Curriculum-based measurement: The emerging alternative. *Exceptional Children*, 52, 219-232.
- Fabrizio, M. A., Pahl, S., & Moors, A. (2002). Improving speech intelligibility through precision teaching. *Journal of Precision Teaching and Celeration*, 18 (1), 25-27.

- Fedeli, D., & Meazzini, P. (2004). *Lettura e ritardo mentale*. Milano: Franco Angeli.
- Fuchs, L. S., & Fuchs, D. (1986). Oral reading fluency as an indicator of reading competence: A theoretical, empirical, and historical analysis. *Scientific Studies of Reading*, 5 (3), 239-256.
- Greer, R. D., & Ross, D. E. (2007). Verbal Behavior Analysis: Inducing and expanding new verbal capabilities in children with language delays. Oral reading fluency as an indicator of reading competence: A theoretical, empirical, and historical analysis. *Scientific Studies of Reading*, 5 (3), 239-256.
- Gunderson, L. (1984). One last word list. *Alberta Journal of Educational Research*, 30 (4), 259- 269.
- Heward, W. L. (2003a). *Exceptional children: An introduction to special education* (7th ed). New York: Prentice-Hall.
- Heward, W. L. (2003b). Ten faulty notions about teaching and learning that hinder the effectiveness of special education. *The Journal of Special Education*, 36 (4), 186-205.
- Hughes, J. C., Beverley, M., & Whitehead, J. (2007). Using Precision Teaching to increase the fluency of word reading with problem readers. *European Journal of Behavior Analysis*, 8 (2), 221-238.
- Iwata, B. A., Bailey, J. S., Neef, N. A., Wacker, D. P., Repp, A. C., & Shook, G. L. (Eds.). (1997). *Behavior analysis in developmental disabilities 1968–1995* (3rd ed.). Lawrence, KS: Society for the Experimental Analysis of Behavior.
- Koegel, L. K., Dunlap, G., & Dyer, K. (1980). Intertrial interval duration and learning in autistic children. *European Journal of Behavior Analysis*, 13, 91-99.
- Kubina, R. M. (2005). The relationship between fluency, rate building and practice: A response to Doughty, Chase, and O'Shields. *The Behavior Analyst*, 28, 73-76.
- Kubina, R. M., Young, A. E., & Kilwein, M. (2004). Examining an effect of fluency: Application of oral word segmentation and letters sounds for spelling. *Learning Disabilities: A Multidisciplinary Journal*, 13, 17-23.
- Lindsley, O. R. (1992). Precision Teaching: discoveries and effects. *Journal of Applied Behavior Analysis*, 25 (1), 51-57.
- Marconi, L., Ott, M., Pesenti, E., Ratti, D., & Tavella, M. (1994). *Lessico elementare. Dati statistici sull'italiano scritto e letto dai bambini delle elementari*. Bologna: Zanichelli.
- Nathan, R. G., & Stanovich, K. E. (1991). The causes and consequence of differences in reading fluency. *Theory into Practice*, 30 (3), 176-184.

- Perini, S., & Bijou, S. W. (1993). *Lo sviluppo del bambino ritardato*. Milano: Franco Angeli.
- Pinnell, G. S., Pikulski, J. J., Wixson, K. K., Campbell, J. R., Gough, P. B., & Beatty, A. S. (1995). *Listening to children read aloud*. Washington, D.C.: Office of Educational Research and Improvement, U.S. Department of Education.
- Riccardi Ripamonti, I., Truzoli, R., & Salvatico, T. (2004). Analisi di efficacia dell'approccio fonologico-lessicale nel trattamento delle difficoltà di letto-scrittura. *Dislessia, 1*, 309-338.
- Sulgrove, M. K., & McLaughlin, T. F. (2004). The effects of additional timed reading on reading rate. *Journal of Precision Teaching and Celeration, 20* (1), 9-16.
- Therrien, W. J. (2004). Fluency and comprehension gains as a result of repeated reading: A meta-analysis. *Remedial and Special Education, 25* (4), 252-261.
- Tressoldi, P. E., Vio, C., Lorusso, M. L., Facoetti, A., & Iozzino, R. (2003). Confronto di efficacia ed efficienza tra trattamenti per il miglioramento della lettura in soggetti dislessici. *Psicologia Clinica dello Sviluppo, 7* (3), 481-493.
- Wechsler, D. (1974). *WISC-R Wechsler Intelligence Scale for Children Revised*. Firenze: Organizzazioni Speciali (Tr. It. V. Rubini e F. Padovani, *WISC-R Scala di Intelligenza Wechsler per bambini - Riveduta*, O.S., Firenze 1986).
- West, R. P., Young, K. R., & Spooner, F. (1990). Precision Teaching: An introduction. *Teaching Exceptional Children, 22* (3), 4-9.
- White, O. R. (1985). Aim\*star wars [setting aims that compete]. *Journal of Precision Teaching, 6* (2), 30-35.
- White, O. R., & Neely, M. (2004). *An overview of Standard Celeration Chart conventions and practices*. Retrieved August 22, 2007 from [http://courses.washington.edu/edspe510/510\\_Readings.htm](http://courses.washington.edu/edspe510/510_Readings.htm).
- Williams, V. (1993). Effects of two teacher presentation rates during small-group social studies instruction on active student response, on-task behavior, and academic achievement by elementary students with severe behavior disorders. *Unpublished master's thesis. The Ohio State University, Columbus*.





## Notes for Contributors

The Journal will publish original papers (not early published nor in press). Papers submitted for publication should be sent in electronic format, using one of the versions of Microsoft Word, through the e-mail address indicated below. A supplementary version in pdf format (built by means of Acrobat Reader), added to the word file, may be useful to allow a clear vision of the format foreseen for printing. The most recent edition of the Publication Manual of the American Psychological Association (Washington, APA), should be used as the style guide for the preparation of the manuscripts.

The first page of the manuscript should give the title, authors' names and affiliations, and the complete mailing address of one of the authors (included fax number and e-mail address). At least three keywords should be indicated.

The abstract should not exceed 200 words. Theoretical aspects, goals and methods, results and a short discussion should be clearly reported.

The text of the paper should clearly indicate the following sections (example for an empirical paper):

1. Introduction
2. Aims and hypothesis
3. Methods: Sample, Instruments, Procedure
4. Data analysis
5. Discussion

Tables and Figures should be in a limited number. They should be typed in a separate page, and they should report a descriptive title (e.g.: Table 3, Figure III) followed by the legend. Illustrations should be made according to the linked models, and kept modifiable for an editorial work. The approximate location of figures and tables should be clearly indicated in the text.

Decimal point should be used both in the tables and the text. For descriptive statistics, correlations, inferential statistics, etc., two decimal digits have to be reported. Omit zero before decimal digits when the value cannot be greater than 1 (e.g., correlations and significance level)

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 (1973a). According to A.P.A. norms, in the quotations with more than one author the symbol & should be used if the quotation is enclosed in parenthesis (Estes & Skinner, 1940), otherwise "and" has to be used: e.g. Estes and Skinner (1940).

For three to six authors, all surnames should be cited the first time the reference occurs (es. Wasserstein, Zappulla, Rosen, Gerstman, & Rock, 1994). Subsequent citations should use *et al.*: Wasserstein et al., 1994. If the authors are more than six, use *et al.* after the six name. For subsequent citations use *et al.* after the first author's name.

References list should be given at the end of the article in alphabetical order, conform to the A.P.A. reference list, as illustrated by the following examples:

- Achinstein, P. (1968). *Concepts of science*. Baltimore: John Hopkins Press.
- Anisman, H., Remington, G., & Sklar, L. S. (1979). Effects of inescapable shock on subsequent escape performance: Catecholaminergic and cholinergic mediation of response initiation and maintenance. *Psychopharmacology*, 61 (1), 107-124.
- Grossman, H. J. (Ed.). (1973). *A manual on terminology and classification in mental retardation* (Rev. ed.). Washington, DC: American Association on Mental Deficiency.
- Harter, M. R., & Aine, C. J. (1984). Brain mechanisms of visual selective attention. In R. Parasuraman & D. R. Davies (Eds.), *Varieties of attention* (pp. 293-319). New York: Academic Press.
- Lanktree, C., & Briere, J. (1991). *Early data on the trauma Symptom Checklist for Children* (TSC-C). Paper presented at the meeting of the American Professional Society on the Abuse of Children, San Diego, CA.
- Piaget, J. (1967). *Biologie et connaissance*. Paris: Éditions de la Pléiade. (Engl. transl., *Biology and Knowledge*. Chicago: University of Chicago Press, 1971).
- Shallice, T. (1972). Dual function of consciousness. *Psychological Review*, 79, 383-393.

Please be sure that all the citation in the text are reported in the bibliography, while references not quoted in the text should not be included.

Footnotes should be avoided as possible. When their use is absolutely necessary, footnotes should be numbered consecutively using superscript numbers for citation in the text, and inserted in the text according to Microsoft Word criteria for notes at the foot of the page.

The Authors have to sign the statements regarding Conflict of Interest, Informed Consent, and Human and Animal Rights. Please follow the instructions included in the linked file.

Correspondence should be addressed to the editorial secretary:

Dr. Tommasa Zagaria, Associazione "Oasi" Maria SS. I.R.C.C.S., via Conte Ruggero 73, Troina, 94018 Italy.  
Phone: ++39-935-936263/ 936233/ 936111; Faxline: ++39-935-653327; E-mail: tzagaria@oasi.en.it.

Research articles submitted for publication will be sent anonymously to two members of the editorial board. The evaluation will be sent to the corresponding author normally within three months after the reception of the version prepared according to the notes for contributors.

The copyright of the accepted articles is retained by the publisher.

Authors will receive two free copies of the issue including the printed article. Reprints may be ordered on a form sent to the authors together with the communication that article is accepted for the publication.

# LIFE SPAN AND DISABILITY