



Faculteit Psychologie en
Pedagogische Wetenschappen

**From quality of support to quality of life in persons with
Autism Spectrum Disorder**

Jo Renty

Promotor: Prof. Dr. Herbert Roeyers

Proefschrift ingediend tot het behalen van de academische graad van Doctor
in de Pedagogische Wetenschappen

2005

ACKNOWLEDGEMENTS

First of all, I would like to express my profound gratitude to my supervisor, Prof. Dr. Herbert Roeyers, who gave me the opportunity to work in his research group. Thank you for your support and guidance on my first steps in academia. You gave me the confidence to seek my own research path in a research group of psychologists. You meticulously read and re-read many versions of my papers and you always generously shared your expertise in autism.

I also owe many thanks to Prof. Dr. Paulette Van Oost, the head of the Department of Experimental-Clinical and Health Psychology. Thank you for your support during these four years and for making our department a stimulating place to work in.

I am grateful to the Flemish Parent Organisation (VVA) and the Special Research Fund of the Ghent University. Without their financial support this research could not have been conducted.

Further, I would like to thank and acknowledge the following persons for their valuable suggestions on my work in the past four years: Prof. Dr. Ann Buysse (UGent), K. Casaer (VVKBuO), M. Herremans (VVA), Prof. Dr. Bea Maes (K.U.Leuven), Dr. Yves Rosseel (UGent), Prof. Dr. Robert Schalock (Hastings College), C. Schiltmans (VVA), D. Serneels (VWV), P. 's Heeren (Kabinet van Onderwijs), J. Theunis (VFSIPH), and Prof. Dr. Geert Van Hove (UGent).

I would like to express deep appreciation to all the organisations and persons who participated in this doctoral research and to the dedicated students who helped me in collecting the data.

Further, I want to express my gratitude to all colleagues of the department for their continuous encouragements, especially during the last few months. Special thanks go to Petra Warreyn for the final proofreading, to Dieter Baeyens, Isabel Degroote, Mieke Meirsschaut, Ruth Raymaekers, Martine Thys, and Ilse Viane for being more than just colleagues, and last, but certainly not least to Kim De Corte, for being such a great roommate (and card player). Your encouragement has been invaluable to me !

My final thanks and personal warmth go wholeheartedly to my family and friends. Without your support I would not have been able to complete this doctoral adventure, at least not in the way I did now. I am grateful to my parents for their endless trust in me and their priceless caring attention.

For and above all, I would like to thank Kristof. During the last months, you made me experience that spousal support is a strong and unique predictor of quality of life.

Jo,
September 2005

TABLE OF CONTENTS

General introduction	1
Part I The quality of support in Flemish schools and services for persons with autism spectrum disorder	19
Chapter 1 Students with autism spectrum disorder in special and general education schools in Flanders	21
Chapter 2 Service provision for persons with autism spectrum disorder in Flanders	39
Part II Support needs and experiences of persons with autism spectrum disorder	59
Chapter 3 Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents	61
Chapter 4 Support needs and experiences in adults with autism spectrum disorder: A qualitative analysis	89
Part III The predictive value of formal and informal support for the quality of life in adults with autism spectrum disorder	111
Chapter 5 Quality of life in adults with autism spectrum disorder: The predictive value of disability and support characteristics	113
Chapter 6 Individual and marital adaptation in men with autism spectrum disorder and their spouses: The role of social support and coping strategies	129
General discussion	149
Nederlandse samenvatting	171
References	177

GENERAL INTRODUCTION

In this general introduction, we introduce the term ‘autism spectrum disorder’ (ASD) and describe the theoretical framework in which the chapters of this doctoral dissertation are situated. Furthermore, we formulate the objectives and research questions of our studies. Finally, we give an overview of the chapters included in this dissertation.

INTRODUCTION

Autistic disorder is a neurodevelopmental disorder with early childhood onset, characterized by a triad of impairments: (1) qualitative impairments in social interaction shown in the use of multiple nonverbal behaviours (such as eye-to-eye gaze, facial expressions, body postures, and gestures to regulate social interaction), a failure to develop peer relationships appropriate to developmental level, a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, and/or a lack of social or emotional reciprocity; (2) qualitative impairments in communication as manifested by a delay in, or total lack of the development of spoken language (without nonverbal compensation), problems with initiating or sustaining conversations with others, stereotyped and repetitive use of language, and/or a lack of varied, spontaneous make-believe play or social imitative play; (3) restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities, as manifested by a preoccupation with particular topics, apparently inflexible adherence to specific, nonfunctional routines or rituals, stereotyped and repetitive motor mannerisms, and/or a preoccupation with parts of objects rather than the whole (DSM IV-TR; American Psychiatric Association [APA], 2000). Autistic disorder, together with Asperger's Disorder and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)¹, fall under the umbrella of 'autism spectrum disorder' (ASD)², a general term referring to the idea of a spectrum of disorders with 'classic Kanner-type autism' with severe learning disabilities at the one end of the continuum and Asperger's Disorder at the other end (Wing, 1996).

Estimates of prevalence rates range from 10 in 10,000 for autistic disorder to 60 in 10,000 for ASD (Fombonne, 2003). The prevalence of the disorder is at least fourfold in boys compared to girls (Fombonne, 2003; Rutter, 2004). The triad

¹ Asperger's Disorder and PDD-NOS are two diagnostic categories for individuals who show some, but not the full complement of impairments necessary to meet the criteria for autistic disorder.

² Although the terms ASD and Pervasive Developmental Disorder (PDD) are often used interchangeably in the literature, the term ASD will be used throughout this thesis. This term provides a clearer representation of the continuity between autistic disorder and related disorders within the spectrum; it explicitly acknowledges the variety of manifestations of the core deficits and thus the need to organize support that is carefully fitted to the individual's unique needs.

of impairments associated with ASD can be recognized on all levels of intellectual ability. Although the proportion of individuals with intellectual disabilities has classically been estimated to be near 75% of the persons with ASD (Fombonne, 2003), this rate has fallen to much lower figures (26%-55%) in some large epidemiological surveys (e.g., Baird et al., 2000; Chakrabarti & Fombonne, 2001).

To a large extent, individuals with ASD demonstrate other developmental patterns in comparison with other persons of the same developmental level. These areas of uniqueness mainly consist of the core symptoms of the triad of impairments associated with ASD. Hurth, Shaw, Izeman, Whaley, & Rogers (1999) hold the opinion that particularly the social deficit sets ASD apart from other developmental disorders, since this impairment serves as an enormous barrier to social learning and responsiveness to teaching instructions. As a consequence, it is of the utmost importance that interventions towards individuals with ASD are carefully fitted to their unique support needs. Although the research on interventions conducted so far has failed to identify one approach that is equally effective or appropriate for all individuals with ASD, various studies (e.g., Hurth et al., 1999; Iovannone, Dunlap, Huber, & Kincaid, 2003) have identified several essential components of effective practices for persons with ASD. Areas of agreement among researchers include, for example, early intervention, individualization, specialized curriculum, and family involvement.

OUTCOME IN INDIVIDUALS WITH ASD AND THEIR FAMILY: THE SIGNIFICANT ROLE OF SUPPORT

ASD is a lifelong disorder, ordinarily diagnosed during early childhood and persisting through adulthood, with no identified etiology or cure. The deficits displayed by individuals with ASD are a pervasive feature of the person's functioning in all situations, although they may vary in degree of severity. Accordingly, research indicates that the diagnosis of ASD poses major challenges to the person concerned and his or her family. Although families of individuals with ASD are often highly situationally stressed, few of them are seriously dysfunctional (Trute, 2003). In the past, there have been numerous studies on the

risk of pathological levels of distress in families of persons with ASD, which have emphasized that distress and problems are an inevitable outcome of having a family member with a disability (Dunst & Trivette, 1986; Koegel et al., 1992; Konstantareas, Homatidis, & Plowright, 1992; Sanders & Morgan, 1997). However, many studies counter this pathological model by acknowledging that there are large variations in responses to the person's disability and, as a result, that it is important to understand the factors accountable for these differences in outcome (e.g., Holland & Holahan, 2003; Pakenham, Samios, & Sofronoff, 2005; Tak & McCubbin, 2002). The double ABCX model of adjustment and adaptation as proposed by McCubbin and Patterson (1983) has been recognized as one of the most influential theoretical frameworks for the study of factors influencing outcome in individuals with a disability and their families. Within this theoretical model, successful adaptation to a stressor is determined by several interacting components: the severity of the stressor (A), the family resources (e.g., social support) (B), the appraisal of the stressor (C), and the coping strategies employed (BC). Although the stress associated with a disability is an important consideration, its impact on the individual and his or her family is considered to be more related to the family resources and to the available coping resources (McCubbin & Patterson, 1983).

Many studies have explored the role of coping resources in general and of social support in particular. Although there is considerable evidence that social support affects psychological well-being (Kessler & McLeod, 1985), the way in which social support asserts this influence is still equivocal. It is not clear whether social support has a direct or rather a buffering effect. The direct effect model advances the assumption that social support is associated with well-being, irrespective of the level of distress. In contrast, the buffering effect model posits that social support acts as a buffer against the demands associated with a stressor; as a consequence, the beneficial effect of social support merely unfolds under the condition of high stress levels. Although both models have acquired empirical evidence, the buffering effect model has been given the most attention in the research literature (Greenberg, Seltzer, Wyngaarden-Krauss, & Kim, 1997).

Existing research has focused on different dimensions of social support that may be available to persons with a disability or their family. Dunst and

Trivette (1990) have described two types of social support systems: (1) formal support³ systems, which include professionals organizations⁴ such as school programmes, outpatient services, residential services, etc.; and (2) informal support systems, which encompass relationships between family members, relatives, neighbours, friends, and community groups. Cohen and McKay (1984) have emphasized that social support will be effective to the extent that the type of support offered meets the specific needs. Given the unequivocal role researchers have ascribed to social support for individuals with a disability and their family, it is of the utmost importance that the quality and the availability of both formal and informal social support are examined. It is widely recognized that the first step in optimizing support is the evaluation of experiences of service users and the exploration of their needs. The views of these most important stakeholders could then be used to inform the formal and informal support network in the development towards better support (Sperry, Whaley, Shaw, & Brame, 1999).

The Program Logic Model as a touchstone for quality evaluation

During the last decades, a fundamental concern with the quality of support for persons with a disability has emerged, resulting in an increased pressure for schools and services to demonstrate and improve quality at all levels of the organization (Harvey, 1996). This quality revolution has brought about significant changes in how people view the purposes, characteristics, responsibilities, and desired outcomes of educational and human service programmes. Major features of these changes are the focus on outcomes rather than on input, being guided by goals related to person-referenced and valued outcomes, redefining clients as customers, and decentralizing authority (Hakes, 2001). Schalock and Bonham (2003) have proposed a Program Logic Model for the evaluation of support provided by organizations. This evaluation model is composed of 5 stages (see Figure 1).

³ The terms ‘formal support’ and ‘professional support’ will be used interchangeably throughout this dissertation.

⁴ The term ‘organization’ will be used throughout this dissertation to refer to both educational and service provisions.

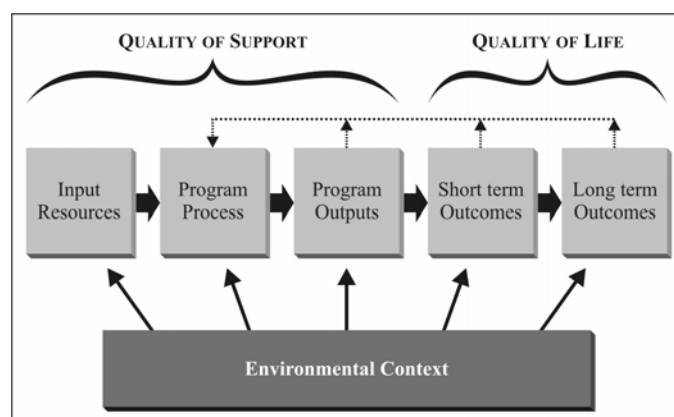


Figure 1
Program Logic Model (Schalock & Bonham, 2003)

The 'input component' (e.g., staff, time, expertise) enables evaluators to focus on the predictors of desired outcomes, rather than concentrating exclusively on the outcomes per se. The focus on potential predictors of successful outcome reflects the significant shift in the quality of life literature from the use of 'between-groups research designs' to the use of 'multivariate, within designs' that attempt to find the factors contributing to better outcome (Gregory, Robertson, Kessissoglou, Emerson, & Hatton, 2001; Schalock, 2001). In a 'between-groups' approach, factors are sought which can discriminate between individuals with a higher and a lower quality of life. For instance, differences in quality of life are attributed to the factor 'disability'. In contrast, quality of life measurement using a 'within design' intends to find predictors of quality of life within one group (e.g. persons with a disability), which enables the formal and informal support network to take the factors into account which potentially enhance people's quality of life. The use of 'multivariate, within designs' stresses the importance of environmental factors as major sources of quality of life enhancement (Schalock, 2000). In terms of support for persons with ASD, the input component may encompass the amount of resources a service or school invests in the creation of an environment which is autism-sensitive.

The 'process component' consists of the determination of goals that the person and his or her family want to achieve, the assignment of staff and other

resources in ways that the person will help to progress towards those goals, and the monitoring of this progress.

The key objective of the 'program output component' is that persons have accomplished the goals that they have set for themselves.

These first three stages of the Program Logic Model on service evaluation involve the evaluation of the quality of support delivered by an organization. However, to date, increased attention is paid to the enhancement of quality of life as the most significant outcome strived for. The Program Logic Model identifies two different stages related to this outcome: short-term and long-term outcomes. Whereas the 'short-term outcomes' refer to the program effects that occur shortly after the program outputs and include for instance satisfaction with the process and outcome, the 'long-term outcomes' are expected to occur several years after the short-term outcomes and are typically associated with one or more domains of quality of life.

There is an emerging consensus that quality of life is a multidimensional construct. Current research suggests that the concept involves at least eight core domains: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights (Cummins, 1996; Felce & Perry, 1995; Hughes & Hwang, 1996; Schalock, 1996, 1997). These eight domains are valued differently by persons and the value attached to each dimension varies across lifespan (Schalock, 2000).

Schalock (1996) suggests to use the quality of life concept as (1) a sensitizing notion that gives us a sense of reference from the individual's perspective, (2) a social construct that provides a model for assessing the core quality of life-domains, and (3) a unifying theme that provides a systematic framework to apply quality of life-oriented policies and practices. This conceptualization of quality of life is consistent with the understanding that quality of life functions as a touchstone for service delivery and policy development (Keith, 2001; Schalock, 1996).

Measuring quality of support

Over a variety of disciplines, it is commonly accepted that quality of support can be measured based on structure (input), process, and output (Donabedian, 1982; Schalock & Bonham, 2003). *Structural measures* are the characteristics of the resources in the organization (e.g., staffing levels, infrastructure, expertise of the staff). The organizational structure may be a root cause of several downstream quality problems and critical to the success of the organization. The main advantage of structural measures of quality of support is the relative ease of measurement. The main disadvantage is that the link between the structural variables and the desired outcome is often indirect (Derose & Petitti, 2003). For example, given the empirical evidence of a correlation between staffing and outcome, staffing levels are often used as a quality indicator of the organizational structure. However, the link between these two variables is rather indirect; it is the intervention carried out by the staff and not merely the presence of the staff that improves outcome.

Process measures are often more appealing to organizations, because they are directly related to what the school or service does. They are apparent, often pointing directly to areas in which the support can be improved. However, there are several arguments against process measures as measures of quality of support. Processes are not necessarily important predictors of outcome, and directing resources (input) at processes that do not necessarily affect the outcome may increase costs and efforts without enhancing quality (Derose & Petitti, 2003). Brook, McGlynn, & Shekelle (2000) state that “process measures are only as good as the evidence that associates them with improved outcome” (p. 284). Also Derose and Petitti (2003) believe it may be difficult to achieve consensus on the indicators of quality processes, especially when the evidence base is poor.

Finally, *output measures* appeal most to organizations because they are most concrete and observable. However, outcomes are also affected by other factors which are not under the control of the organization (such as past experiences and the individual’s personal value system). As a result, conclusions on the quality of support based on output measures may be invalid. Moreover, it may be difficult to assign responsibility of certain outcomes to a single

organization, since persons with disabilities often appeal to different organizations (Lohr, 1990; Schalock & Bonham, 2003).

Measures of quality of support are most successful in tapping the actual quality of the support delivered when they are evidence-based (Derose & Petitti, 2003). Although there is an enormous amount of publications on possible treatments for ASD (some even claiming to result in recovery from the disorder), there are few, if any, interventions with a sound evidence base. As a consequence, standards of support for persons with ASD have to be based on the areas of effective practices, that are well-documented and that researchers have agreed upon (Hurth et al., 1999; Iovannone, Dunlap, Huber, & Kincaid, 2003).

Measuring quality of life

Efforts to measure quality of life go back at least as far as Thorndike (1939) and ever since researchers have been reporting on quality of life measurement (Hughes, Hwang, Kim, Eisenman, & Killian, 1995). Depending on the investigator's focus and purpose, the core dimensions of quality of life can be measured using a 'multi-methodological perspective'. The foundation of the use of multiple measurement techniques lies in four premises: (1) quality of life is a multidimensional construct, (2) individuals differ in their ability to understand and respond, (3) researchers use quality of life data for different purposes, including self-report, evaluation, description, and comparison, and (4) quality of life measurement can focus either on an individual or a group (Schalock, 1996). Specific techniques include discrepancy analysis, multidimensional scales, ethnographic studies, and direct behavioural data. Each of these techniques is briefly discussed below.

Discrepancy analysis, the evaluation of the goodness-of-fit. Quality of life is sometimes conceptualized theoretically and measured as the goodness-of-fit of a person's needs and the satisfaction of those needs (Dennis, Williams, Giangreco, & Cloninger, 1993; Keith, 2001). A fit or a match between the characteristics of a person and the demands of the environment is important in achieving positive individual outcomes. A mismatch between these two constructs would decrease

anyone's quality of life, regardless of the disability one has (Schalock, 1994). Ecological analyses have been proposed to measure the goodness-of-fit between a person's environment, the available resources and the stressor. Heal, Borthwick-Duffy, and Saunders (1996) further define quality of life as the lack of a discrepancy between needs and their fulfilment through one's own control over resources (such as social support) to satisfy those needs. Evaluation in terms of this definition requires a tool to compare objectively the disparity or discrepancy between an individual's needs and the degree and frequency in which they are met. According to Schalock (1996), discrepancy analyses are an appropriate means to measure satisfaction, personal needs, and indicators for programme development/change.

Multidimensional scales. Standardized instruments are used frequently to assess a number of indicators or domains reflective of quality of life. Many authors comment on the significance of integrating both the objective and subjective components into quality of life measurement (Cummins, 2000; Felce, 1997; Schalock, 2000). Restricting quality of life measurement to either the objective life circumstances or subjective well-being involves serious problems. On the one hand, quality of life as a sum of the objective measurable life circumstances experienced by an individual, implies that there are clear objective standards available by which to assess quality of life (e.g., physical health, income, material standard of living, social network). However, the existence of 'objective' standards by which one can define a reasonable quality of life is questionable (Edgerton, 1996). Moreover, this approach ignores the significance of subjective appraisal and personal satisfaction to quality of life assessment (Felce & Perry, 1995). On the other hand, evaluating quality of life solely by means of personal satisfaction is neither accepted uncritically. Edgerton (1996) and Cummins (1996; 2000; 2001) have reported on subjective quality of life assessment and problems associated with it. A fundamental problem with subjective appraisal as a quality of life indicator is that life satisfaction and subjective quality of life are under homeostatic control. There is a growing body of evidence that satisfaction is relatively stable over time and that most people consistently rate their subjective well-being above the mid-point of scales, except under strong negative external conditions. Major life events that exceed the adaptive capacity of the homeostatic system may temporarily result in changes in expressed life satisfaction, but as soon as people

accustom themselves to these changed objective life circumstances they rebound to the initial level of subjective well-being. Consequently, satisfaction ratings are fairly independent from objective life circumstances, as long as these objective conditions do not abruptly exceed the adaptive capacity of the homeostatic system. The integration of both objective and subjective components implies that the assessment of quality of life is sensitive to the individual's appraisal of his or her objective life conditions, while guaranteeing an independent and neutral perspective on those life conditions (Felce & Perry, 1995). Therefore, the use of multidimensional scales is suitable for satisfaction studies, outcome assessments, policy development, and research. On the other hand, multidimensional scales are considered to be less appropriate for needs assessment and programme development (Schalock, 1996).

Ethnographic studies. The use of ethnographic studies involves naturalistic, unobtrusive observation of the lives of people with a disability in the natural context of their ongoing lives. Edgerton (1996) has recommended prolonged contact with people with a disability in their natural context of working, living, and recreation at more or less unpredictable intervals, with the objective of acquiring fuller understanding of their personal life circumstances and the satisfaction with their lives. Besides the measurement of satisfaction levels, Schalock (1996) recommends the use of ethnographic studies for the purpose of needs assessment, programme development/change, and research.

Direct behavioural data. Some researchers have used indirect measures of quality of life, such as performance-based assessments, which are conceived as objective indicators of the core quality of life dimensions. Persson (2001), for example, used a measure of behaviour and independence in a sample of adult men with ASD to assess their quality of life. According to Schalock (1996), direct behavioural data are useful for the measurement of satisfaction levels, outcomes assessment, programme development/change, and research.

AIMS OF THE PRESENT DISSERTATION AND CHAPTER OVERVIEW

This dissertation elaborates on both quality of support and quality of life in persons with ASD. The main objectives of the present dissertation are threefold. Firstly, we want to examine the quality of support in Flemish organizations that provide education and/or support for persons with ASD. The quality of support will be assessed using structural and process measures, which are reflective of the ‘input’ and the ‘process component’ of the Program Logic Model of Schalock and Bonham (2003). Secondly, we want to assess the discrepancy between the support needs of persons with ASD and the degree and frequency in which they are met, which refers to the ‘short-term outcome’ component of Schalock and Bonham’s model. Thirdly, we want to investigate the predictive value of support characteristics for quality of life in adults with ASD, which will be measured by means of a multidimensional scale [Chapter 5] and direct behavioural data [Chapter 6]. In correspondence with these main objectives, three major parts can be distinguished in this dissertation. Table 1 presents a short overview of the chapters.

The first part aims to describe the current educational and service provision for persons with ASD in Flanders. Based on the theoretical framework of the Program Logic Model (Schalock & Bonham, 2003), Chapter 1 and 2 measures the quality of support for persons with ASD, targeting on the ‘input’ and ‘process component’ of organizations. The presence of evidence-based areas of effective practices for persons with ASD is enquired and factors associated with the presence of effective practices (e.g., school or service type, school population) are identified.

Chapter 1 describes the educational provision for students with ASD in Flanders. In the past, many studies have reported on the best educational placement for children with disabilities. Particularly the educational inclusion of students with a disability has been a hotly debated topic (Harrower, 1999). Although the idea of inclusion has been supported by many studies in the field of intellectual disabilities, some researchers, practitioners, and parents have expressed their doubts regarding the inclusion of children with ASD in general education classrooms (Kasari, Freeman, Bauminger, & Alkin, 1999; McGregor & Campbell, 2001; Mesibov, 1999; Mesibov & Shea, 1996; Panerai, Ferrante, & Zingale, 2002; Scruggs & Mastropieri, 1996). According to them, students with ASD often require an alternative educational approach than that applied to students without ASD. The aim of Chapter 1 is to examine, from the schools' point of view, the way in which special and general education schools in Flanders adapt their educational programme and environment to the specific support needs of students with ASD.

Similarly, *Chapter 2* provides an overview of the current service provision for persons with ASD in Flanders. Several essential components of effective practices for individuals with ASD are examined: the individualization of support, a specialized curriculum, a supportive and comprehensible environment, family involvement, and highly trained staff (Howlin, 1998; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999; Iovannone, Dunlap, Huber, & Kincaid, 2003; National Research Council, 2001). The extent to which these essential components of effective practices occur in both inpatient and outpatient services for persons with disabilities is described.

Whereas the first part of this dissertation elaborates on the quality of support for persons with ASD, the second and the third part explore the quality of life of persons with ASD, respectively on the basis of the 'short-term' and the 'long-term outcomes' components of Schalock and Bonham's model (2003). In the second part of this dissertation, the short-term outcomes of children and adults with ASD are investigated by means of a satisfaction study.

Table 1
Chapter overview

	Chapter	N	Sample	Method
Part I	Chapter 1	172	Special schools	Survey Interview
	Chapter 2	70 352	General education schools Services	Survey Interview
Part II	Chapter 3	244	Parents of children with ASD	Survey Interview
	Chapter 4	58	Adults with ASD ¹	Camberwell Assessment of Need
Part III	Chapter 5	58	Adults with ASD ¹	Autism-spectrum Quotient Interpersonal Support Evaluation List Camberwell Assessment of Need Quality of Life Questionnaire
	Chapter 6	21 21	Adult men with ASD Spouses of men with ASD	Autism Spectrum Quotient Inventory of Social Supportive Behaviours Social Provisions Scale Camberwell Assessment of Need Ways of Coping Questionnaire Symptom Checklist – 90 Dyadic Adjustment Scale

¹ *Note.* These chapters are based on the same sample.

Chapter 3. The significance of parental satisfaction as an indicator for the effectiveness of intervention programmes for children with ASD has been recognized by many researchers (e.g. Boyd & Corley, 2001; Hancock & Kaiser, 2001; Mesibov, 1997). Sloper (1999) notified that a lack of any overall view on support needs of persons with disabilities commonly results in support which is service- rather than needs-led. Whilst it is clear that research on parental satisfaction and support needs can provide useful information for service development, few evaluation studies in the field of ASD have used parental satisfaction as a criterion for the evaluation of professional support. In this chapter, we explore the specific support needs of children with ASD (as reported by their parents) and the parental satisfaction with the professional support received for the child. Next to descriptive measures, qualitative analyses of interviews are provided in order to explore the particular experiences and solitudes of the parents in depth.

Chapter 4. This chapter reports on a descriptive study examining the subjective support needs and experiences of high functioning adults with ASD. Whereas the previous chapter examines satisfaction with formal support and formal support needs of children with ASD, the current chapter investigates both formal and informal support needs and experiences. The Camberwell Assessment of Need (CAN; Phelan et al., 1995; McCrone et al., 2000) is used as a standardized measure for the assessment of subjective support needs and experiences and enables us to analyse the goodness-of-fit between the person's needs and the fulfilment of his or her needs. We report both on the descriptive findings of the CAN interviews and on the qualitative in-depth analyses of the interview transcripts.

The previous chapters focus on support provisions and support experiences of service users with ASD, rather on a descriptive level. The final part of the dissertation investigates the association between support characteristics on the one hand and long-term outcomes in adults with high functioning ASD on the other hand. In line with Schalock's (2000) recommendation to use a multivariate within research design, the studies described in both chapters of this third part aim to identify factors associated with higher levels of quality of life in respectively adults with ASD and couples with one partner having ASD.

Chapter 5. In this chapter, we examine factors associated with better long-term outcome in high functioning adults with ASD, using the conceptual model of Quality of Life (Schalock et al., 2002). Quality of life was measured using a standardized multidimensional scale, comprised of both subjective and objective components. Though earlier studies on outcome in adults with ASD have commonly reported on the predictive value of disability characteristics, Chapter 5 aims to find evidence for the importance of environmental factors (such as social support) as the supreme source of quality of life enhancement (Schalock, 2000).

Chapter 6. Although there are no research findings available on the prevalence of persons with ASD being a parent, clinical observations and research on the broader ASD phenotype (Rutter, 2000) suggest it concerns a group which is commonly overlooked. However, symptoms associated with ASD (such as social and communicative impairments) may implicate severe levels of stress in adults with ASD having a family and in their spouses. Similar to Chapter 5, the present chapter aims to identify factors associated with successful long-term outcomes in married adults with ASD and their spouses. Quality of life was measured using direct behavioural scales that referred to both individual and marital well-being. Predictors for outcome were chosen in correspondence with the double ABCX model (McCubbin & Patterson, 1983), which has been used in many empirical studies investigating outcome in families coping with a disability.

The *general discussion* contains an integrated overview of the main findings regarding the three major themes that run through the present dissertation. Limitations as well as implications for clinical practice are discussed. Finally, directions for future research are suggested.

It should be noted that this dissertation consists of several papers, which have been accepted for publication, are under editorial review, or have been submitted for publication. Since each of the papers is a self-contained manuscript, partial overlap between the chapters may occur.

Part I

THE QUALITY OF SUPPORT IN FLEMISH SCHOOLS AND SERVICES FOR PERSONS WITH AUTISM SPECTRUM DISORDER

CHAPTER 1

STUDENTS WITH AUTISM SPECTRUM DISORDER IN SPECIAL AND GENERAL EDUCATION SCHOOLS IN FLANDERS¹

ABSTRACT

This study investigated accessibility and quality of the Flemish school system for students with autism spectrum disorder (ASD). A questionnaire was sent to all special schools ($n = 272$) and a sample of general education schools ($n = 140$) in Flanders (Belgium). The results ensuing from the 172 special schools and 70 general education schools that participated in this study has demonstrated that special education does not necessarily provide the most beneficial environment for the student with ASD. Special schools stating that they adapt their educational programme to the needs of students with ASD and general education schools put more effort into dealing with ASD-specific pedagogical and organizational issues than special schools without ASD-specific education. Due to the organizational and pedagogical specificity of appropriate education for students with ASD, it seems that schools trying to adjust to the special needs of students with ASD often need more additional financial and infrastructural resources in order to optimize the education for students with ASD.

¹ Renty, J., & Roeyers, H. (2005). Students with autism spectrum disorder in special and general education schools in Flanders. *British Journal of Developmental Disabilities*, 51, 27-39.

INTRODUCTION

In the past, students with disabilities were mainly educated in special schools, because segregation of persons with disabilities in general was a given fact (Kavale & Forness, 2000). Nevertheless, the educational inclusion of students with disabilities has been a hotly debated topic for decades (Harrower, 1999). Theoretical arguments concerning social development and legal issues related to the civil rights movement, have largely given entrance to the idea of inclusion of students with disabilities in general education classrooms (Harrower & Dunlap, 2001). Inclusion for students with disabilities has been strongly supported by some researchers and practitioners in both general and special education (Brucker, 1994; Mamlin, 1999). According to its advocates, the benefits of inclusion are: increased expectations by teachers of the learning potential of the included students, behavioural modelling of normally developing peers, more learning, increased self-esteem, more accepting attitudes on the part of peers, and less isolation and stigma for disabled students and their families (Banerji & Dailey, 1995; Mesibov & Shea, 1996; Peetsma, Vergeer, Roeleveld, & Karsten, 2001). Other researchers are more sceptical about inclusion of all students with disabilities. They suggest that less severely handicapped students with fewer behavioural problems are the ones who typically benefit most from more integrated settings, while many students with more severe disabilities would benefit from more segregated and specialized programmes, considering their very specific needs (Carlberg & Kavale, 1980; Fuchs & Fuchs, 1995; Madden & Slavin, 1983; McLeskey, Henry, & Hodges, 1999; Waldron & McLeskey, 1998).

Some researchers (e.g., Harrower & Dunlap, 2001; Kasari, Freeman, Bauminger, & Alkin, 1999; Mesibov & Shea, 1996; Myles, Simpson, Ormsbee, & Erikson, 1993) assessed inclusive educational programmes for students with autism spectrum disorder (ASD) in particular, but most research on inclusive education concerns students with other disabilities than ASD.

Autism is characterized by severe qualitative impairments in social interaction and communication and restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities (DSM IV-TR; American Psychiatric Association [APA], 2000). In this article the term ASD will be used to refer to a

broader categorization of disorders related to autism. ASD includes autism, Asperger's Disorder and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). The latter two disorders show some but not the full complement of impairments necessary to meet the criteria for autism (Wing, 1996). The diagnostic label ASD is preferred in Flanders since the validity of Asperger's Disorder as a distinct diagnostic category is disputed (for an overview: see Macintosh & Dissanayake, 2004). Estimates of prevalence rates range from 10 in 10,000 for autism to 60 in 10,000 for ASD (Fombonne, 2003).

Because of the very nature of the disorder, many students with ASD seem to require an alternative educational approach than that applied to students without ASD. Where for instance verbal explanations, gestures, the use of abstract concepts, modelling, and social rewarding may be beneficial educational techniques for other students, this way of instruction may confound students with ASD (Mesibov & Shea, 1996; Panerai, Ferrante, & Zingale, 2002). While there is considerable evidence that children with disabilities benefit from having contact with less disabled or 'sound' peers, the nature of ASD itself could minimize the influence that the other children present in the classroom have as role models (Mesibov, 1999).

Not only researchers seem to have doubts about the beneficial outcome of educating students with ASD in a general education environment. Kasari et al. (1999) conducted a study that examined the effect of the child's diagnosis (autism vs. Down syndrome) on parental perceptions of inclusion of their own disabled child. Parents of children with Down syndrome were more likely to accept inclusion for their children, while parents of children with autism had reservations about educational inclusion (both for academic and nonacademic activities). Over half of the parents thought that their children's current educational needs could not be adequately met in inclusive schools. Parents of children with autism were significantly more likely to regard the teachers as being the main advantage of their child's current special education. Above all, the specialist training of the teachers in special schools and the specialized teaching approach were decisive. General education teachers admit that they lack necessary skills, training, time, and resources to implement inclusive education for children with ASD in their classroom (Scruggs & Mastropieri, 1996). A study of McGregor and Campbell

(2001) showed that only a minority of general education teachers believes that students with ASD should be integrated.

Students with autism or a related disorder appear to learn best in highly structured environments with lots of visual support and few distractions (Schreibman, 1988; Peeters, 2000). The best environments are those where learning can occur individualized and skill-oriented, where predictability exists, and where antecedent conditions and consequent events responsible for erratic responding are identified and managed (Zager, Shamow, & Schneider, 1999). Therefore, and for reasons mentioned above, specialized instructional techniques and learning environments are often recommended for these students.

Despite the fact that researchers, parents, and practitioners have doubts about the beneficial outcome of general education for children with ASD, we agree with Mesibov (1999) that it is not the single classroom model that is most important in choosing the best educational option for students with ASD, but the quality of the instruction delivered in that classroom. In the present study we investigated 1) to what extent special and general education schools in Flanders (the Dutch speaking part of Belgium) make an effort to deliver high-quality education to students with ASD and adapt the learning environment to the unique needs of these students, and 2) the accessibility of these schools for students with ASD.

The Belgian special education system

Although special education started in the last part of the 19th century in Belgium, it took until 1970 before the Special Education Law recognized these special schools as an independent and specific form of education for students with various kinds of disabilities. There are 8 school types for special education in Belgium, designed for different target groups. Type 1 provides education for students with mild mental disabilities, type 2 for students with moderate and severe mental disabilities, type 3 for students with behavioural problems, type 4 for students with physical disabilities, type 5 for students who are hospitalized, type 6 for students with visual disabilities, type 7 for students with auditory disabilities

and severe language problems and finally, type 8 for students with learning disorders. Despite the well-developed network of special schools in Belgium, there is no formalized special school type for students with ASD. As a result, students with ASD are scattered over different types of special schools, mainly type 1, type 2, type 3, and type 7. Dependent on the motivation of the schools, some special schools retrain and apply for professional help to increase their expertise in educating students with ASD, while other special schools approach students with ASD similarly as students with any other disability. In other words, providing appropriate ASD-specific education in Belgium is a case of voluntarily restricting expenditure in other parts of the school for the benefit of a growing expertise in ASD-specific education.

Besides this fully segregated form of education in special schools, the Belgian school system allows students with disabilities to go to a general education school, possibly with support from a teacher of a special school. In this integrated form of education, students weekly receive 2 to 4 hours support from the special school. Despite the fact that this – so-called – integrated education has been provided for by law since 1986, it is only during the last few years that students with ASD are actually applying for this form of support in general education schools.

METHOD

Data collection

To identify current levels of educational support for students with ASD in special and general education schools in Flanders, a questionnaire was compiled, based upon a review of literature about service evaluation (Nesbitt, 2000; Sperry, Whaley, Shaw, & Brame, 1999). The questionnaire covered six main categories (for detailed information, see Table 1).

The data gathered from the questionnaires were supplemented with information obtained from interviews we carried out with key professionals in 10

special schools. The same topics as the ones in the questionnaire were discussed in more depth. The professionals we interviewed were the coordinators responsible for the education of students with ASD. Two inclusion criteria were used to select a random sample of 10 special schools that would be contacted to participate in the interviews: firstly, the schools had to mention that they adapt their education programme to the needs of students with ASD and secondly, more than 10% of the students had to be diagnosed with ASD. The 10 interviews, each lasting about an hour and a half, were audio-recorded and later transcribed verbatim. The data obtained from the interviews were analyzed under the main headings to detect patterns of opinion and to illustrate the views and experiences of the respondents.

Participating schools

All 277 special schools in Flanders and 142 general education schools where students with ASD were registered, received the questionnaire by mail. The response rate of the special schools amounted to 62% (68% primary schools and 32% secondary schools). The response rate of the general education schools was 49% (79% primary schools and 21% secondary schools).

A drop-out analysis was carried out by telephone for a random sample of 39 special schools that did not return the questionnaire. During the telephone conversation we inquired about the number of students in the school with a diagnosis of ASD. The percentage of schools that had students with a formal diagnosis of ASD was 79% and 74% for participating and non-participating schools respectively ($\chi^2(1) = 0.414, p = .524$). The consideration that only special schools with students with ASD would be likely to fill in the questionnaire proved to be wrong.

In 92% of all special schools involved in this study, students with formally diagnosed or suspected ASD were enrolled in the school. Given the focus of this study, the remaining 8% of schools that had no students with ASD were excluded from further analyses. Since only the general education schools that had students with ASD on their register were included in this study, this delineation did not need to be made for the general education schools.

Table 1
Detailed information about the questionnaire

Category	Items in the questionnaire
1. Descriptive information about the school	<ul style="list-style-type: none"> ▪ Type of school ▪ Capacity of the school ▪ Number of students with diagnosed/suspected ASD in the school ▪ Number of students (with/without ASD) on waiting list ▪ Number of enrolments of students with ASD refused annually
2. Diagnosis of ASD	<ul style="list-style-type: none"> ▪ Diagnostic label of students with ASD in the school
3. Educational resources for students with ASD	<ul style="list-style-type: none"> ▪ Availability of ASD-specific approach in the school ▪ Availability of one-to-one-tutoring for students with ASD ▪ Availability of alternative forms of communication for students with ASD (instead of spoken language) ▪ Adaptations in the organization of the physical environment for students with ASD ▪ Availability of therapy for students with ASD ▪ Availability of external support for students with ASD within the school
4. Involvement of the parents	<ul style="list-style-type: none"> ▪ Frequency of contact with the parents of students with ASD ▪ Type of contact with the parents of students with ASD
5. General knowledge and training about ASD	<ul style="list-style-type: none"> ▪ Evaluation of ASD-specific knowledge regarding causes and prevalence, diagnostics, prognosis, assessment, and appropriate education and support. ▪ Availability of ASD training courses
6. Future needs and expectations	<ul style="list-style-type: none"> ▪ General appraisal of delivered education and support for students with ASD ▪ Prior needs to optimize education and support for students with ASD

Table 2 shows that students of the whole range of ASD are represented in the special and general education schools that finally were included in the analyses.

Table 2
Percentage of (participating) general education schools and special schools where students with a diagnostic label of autism, Asperger's Disorder, PDD-NOS and ASD are enrolled

	General education school (%)	Special school (%)
Autism	38	58
Asperger's Disorder	33	24
PDD-NOS	1	24
ASD	58	89

RESULTS

Table 3 shows the number of students with formally diagnosed or suspected ASD in special and general education schools in Flanders.

As the table indicates, there are marked differences between special and general education schools as regards the size of the school population and the number of students with ASD, there being a larger proportion of students with ASD in special schools. Given this concentration of students with similar impairments in special schools, one would expect the special schools to put considerably more effort into the adaptation of education for students with ASD as compared to general education schools. However, the results of our study concerning ASD-specific adaptations indicate that also general education schools make an effort to provide properly adapted education for students with ASD.

Table 3
Means (M) and Standard Deviations (SD) of the total school population, the number of students with ASD, and the number of students with suspected ASD in general education schools and in special schools

	General education school		Special school	
	Primary	Secondary	Primary	Secondary
Total school population				
<i>M</i>	190.16	653.09	140.00	138.90
<i>SD</i>	127.94	318.94	79.52	96.62
Students with ASD				
<i>M</i>	1.69	2.27	8.86	10.33
<i>SD</i>	1.59	1.27	11.03	14.48
Students with suspected ASD				
<i>M</i>	1.29	0.73	4.22	3.60
<i>SD</i>	1.46	1.42	4.99	4.15

Adaptations in special and general education schools for students with ASD

Of all the special schools where students with (suspected) ASD were enrolled, 44% mention that they pay special attention to the unique needs of these students. Table 4 illustrates that the special schools with an ASD-specific approach put considerably more effort than other special schools and general education schools into adapting the educational environment to the needs of students with ASD. This special attention consists mainly of one-to-one tutoring, alternative forms of communication with the student with ASD (instead of spoken language), and an adapted organization of the physical environment. However, there is not much difference between the general education schools and special schools without ASD-specific education as far as adapting the educational environment to the needs of students with ASD is concerned.

Table 4
Differences between special and general education schools in ASD-specific adaptations

	Special schools with ASD- education (%)	Special schools without ASD- education (%)	General education schools (%)	$\chi^2(2)$	<i>p</i>
One-to-one-tutoring	49 ^a	11 ^b	4 ^b	47.99	.000
Alternative communication					
Written words	83 ^a	53 ^b	33 ^b	35.32	.000
PECS (Picture Exchange Communication System)	94 ^a	57 ^b	59 ^b	29.03	.000
Drawings	64 ^a	46 ^a	30 ^b	15.95	.000
Photographs	77 ^a	40 ^b	14 ^c	55.80	.000
Objects	58 ^a	13 ^b	7 ^b	56.10	.000
Speaking with support of gestures	49 ^a	14 ^b	0 ^c	53.66	.000
Task analyses	75 ^a	31 ^b	20 ^b	48.61	.000
Day schedule	96 ^a	80 ^b	74 ^b	12.17	.002
Diary	74	70	54	6.71	<i>ns</i>
Week schedule	84 ^a	64 ^b	61 ^b	10.00	.007
Year schedule	58 ^a	30 ^b	24 ^b	19.27	.000

Table 4 (continued)
Differences between special and general education schools in ASD-specific adaptations

	Special schools with ASD- education (%)	Special schools without ASD- education (%)	General education schools (%)	$\chi^2(2)$	<i>p</i>
Scheme with photos of present teachers	81 ^a	19 ^b	10 ^b	90.44	.000
Organization of the environment					
Modifications in classroom	96 ^a	57 ^b	21 ^c	78.56	.000
Modifications in dining hall	36 ^a	3 ^b	4 ^b	40.16	.000
Modifications in play ground	33 ^a	7 ^b	6 ^b	25.86	.000
Specially designed materials	81 ^a	21 ^b	19 ^b	72.04	.000
Adapted media	61 ^a	26 ^b	11 ^b	40.93	.000

Note. Percentages in the same row that do not share superscripts differ significantly at $p < .01$ using a $\chi^2(1)$ -test. The superscript *b* indicates “significantly different” from the *a* and *c* value; *c* indicates a significant difference from the *a* and *b* value. Two values with the same superscript indicate no significant difference.

In line with the extensive adaptations in special schools with ASD-specific education, it is to be expected that these schools put considerable effort into adapting their programme to the needs of students with ASD. Consequently, it is not surprising that these schools appeal more than other special schools to staff of the residential part of the school ($\chi^2(1) = 7.71, p = .005$) and to volunteers ($\chi^2(1) = 14.76, p = .000$) to support students with ASD. During the interviews we conducted with some key professionals in special schools, they reflected that the organization of ASD-specific education would hardly be feasible without the support of the staff of the residential part of the school, the staff from other classes, and volunteers. This extra support is mainly needed during less structured moments (e.g., lunch, playtime, extramural activities). Furthermore, with respect to learning activities, schools with ASD-specific education frequently mentioned that they have to economize on staff and space in other classes for the benefit of classes with ASD-specific education (i.e. in ASD-specific classes there are less students in a relatively larger classroom and with relatively more teachers than in the other classes).

Although special schools without ASD-specific education and general education schools do not differ in communication and environment adaptations, the latter mention more often that they seek external support for the education of students with ASD ($\chi^2(1) = 19.38, p = .000$).

Parental Involvement

Similarly, comparisons of parental involvement revealed significant differences between special schools with and without ASD-specific education ($F(1,136) = 25.94, p = .000$). The group differences were in the direction of parental involvement being higher for the group of special schools with an ASD-specific approach. When comparing general education schools with special schools without ASD-specific education, it is noticeable that there is significantly less parental involvement in the latter group of schools than in the general education schools ($F(1,137) = 6.41, p = .012$).

Autism-specific knowledge and training

The evaluation of the autism-specific knowledge of the staff was measured by five categories of knowledge on a 5-point Likert scale: a) causes and prevalence of ASD, b) diagnostics of ASD and appropriate diagnostic instruments, c) assessment of persons with ASD, d) appropriate education and support of persons with ASD, and finally, e) the prognosis of ASD.

Table 5 illustrates that the average scores of autism-specific knowledge of the school head, the paramedics, the teachers and the assistant teachers were significantly higher in special schools with ASD-specific education than in the other special schools. This significant difference did not apply to psychologists/pedagogues. Furthermore, there were no significant differences between general education schools and special schools without ASD-specific approach as regards ASD-specific knowledge of the school head and the teachers. Both groups judge the ASD-specific knowledge to be relatively low in their schools.

In almost all special schools with ASD-specific education (97%) staff members were given the opportunity to follow training concerning ASD, whilst only 61% of the special schools without ASD-specific education provided this opportunity ($\chi^2(1) = 28.82, p = .000$). In the group of general education schools, 73% followed ASD-specific training, which tends to be a higher percentage than in special schools without ASD-specific approach ($\chi^2(1) = 2.64, p = .072$). Nevertheless, all schools involved in this study had one or more students with a diagnosis of ASD or suspected ASD. Keeping in mind that the quality of life of individuals with ASD largely depends on the autism-specific knowledge and the expertise and skills that professionals have in modifying their communication style and the environment to the needs of people with ASD, training should be regarded as a key factor in developing good practice for persons with ASD (Peeters, 2000).

Table 5
The evaluation of autism-specific knowledge of the staff in special and general education schools

	Special schools with ASD- education <i>M (SD)</i>	Special schools without ASD- education <i>M (SD)</i>	General education schools <i>M (SD)</i>	<i>df</i>	<i>F</i>	<i>p</i>
School Head	3.04 (.81) ^a	2.34 (.69) ^b	2.55 (.69) ^b	2,213	17.361	.000
Paramedics	3.35 (.76) ^a	2.60 (.77) ^b	-	1,139	33.744	.000
Psychologists/ Pedagogues	3.66 (.77)	3.28 (.62)	-	1,77	6.102	<i>ns</i>
Teachers	3.23 (.89) ^a	2.18 (.71) ^b	2.42 (.81) ^b	2,218	34.552	.000
Assistant teachers	3.26 (.96) ^a	2.07 (.92) ^b	-	1,33	13.841	.001

Note. Means in the same row that do not share superscripts differ significantly at $p < .01$ using a post hoc-test (Scheffé)

Table 6
General appraisal of quality of the education delivered to students with ASD in special and general education schools.

	Special schools with ASD- education <i>M (SD)</i>	Special schools without ASD- education <i>M (SD)</i>	General education schools <i>M (SD)</i>	<i>df</i>	<i>F</i>	<i>p</i>
Quality score	6.65 (1.61) ^a	3.88 (1.81) ^b	5.15 (2.19) ^c	2,199	37.517	.000

Note. Means that do not share superscripts differ significantly at $p < .01$ using a post hoc-test (Scheffé)

All schools were asked to rate themselves on a 10-point scale, which represented the quality of the education for students with ASD in their school. A score of 10 indicated the ideal education in ideal circumstances for students with ASD. The average scores of the schools are illustrated in Table 6.

Accessibility of special and general education schools for students with ASD

The results of our study highlight clear differences between special and general education schools as far as accessibility is concerned. One of the major accessibility difficulties of special schools in Flanders lies in the long waiting lists. Thirteen percent of the special schools has a waiting list. Significant more schools that adapt their educational programme to the needs of students with ASD have a waiting list (23%) than schools without ASD-specific education (5%) ($\chi^2(1) = 11.44, p = .001$).

Another possible cause of limited accessibility of specialized ASD-education is the fact that many special schools in Flanders require a formal diagnosis of ASD as a prerequisite for being eligible to request ASD-specific support within the school. However, results of previous research carried out among parents of children with ASD (Renty & Roeyers, 2004) indicate that it is not easy to consult diagnostic centres, due to the long waiting lists and the limited availability of diagnostic centres. People have to consult an average of 3.29 ($SD = 1.76$) diagnostic centres and have to wait on average for 2.12 years ($SD = 2.12$) before ASD is diagnosed. Meanwhile, the child has reached 5.78 years ($SD = 2.41$). Considering that several studies have demonstrated that the diagnosis of ASD is reliable and stable from the age of 2 (Charman & Baird, 2002; Moore & Goodson, 2003), the average age at which a diagnosis is made is unacceptably high in Flanders. Since special schools with an ASD-specific approach often demand a formal diagnosis of ASD, these diagnostic problems impede easy access to proper support and education.

In view of the fact that general education schools have a lower threshold, these accessibility problems clearly occur less frequently in these schools.

Moreover, 94% of these schools declare that so far they have never refused to enrol a student with ASD.

DISCUSSION

Considering the increasing number of publications and movements advocating the educational inclusion of students with disabilities, it seems that the value of special education has shifted to the background (Palmer, Fuller, Arora, & Nelson, 2001). Nevertheless, in reality, special education is still a frequently chosen option for students with disabilities in many countries (Ainscow, 1997; McLeskey et al., 1999). Although the goals and values underlying the philosophy of inclusion are undeniably laudable, some researchers dispute the benefit of general education for students with more severe disabilities (Carlberg & Kavale, 1980; Fuchs & Fuchs, 1995; Madden & Slavin, 1983). However, the results of our study have demonstrated that choosing a special school does not automatically implies the best educational environment for students with ASD. On the one hand, of all the special schools that educate students with ASD, only 44% confirmed they had an adjusted educational programme that takes into account the unique needs of students with ASD. The specialized approach in these schools manifests itself in areas of alternative communication, the educational environment, parental involvement, and finally, autism-specific knowledge and training. On the other hand, we found that, in comparison with special schools without ASD-specific education, general education schools tend to create more opportunities for the staff to follow ASD-specific training and they often work more closely together with parents and external supporters to adapt their education to the needs of students with ASD. Moreover, general education schools try as hard as special schools without ASD-specific education to adapt the learning environment and communication to the needs of students with ASD. In view of the differences in environmental and communicative needs of the respective school populations, this is a creditable effort of the general education schools.

PRACTICAL IMPLICATIONS

Although the present study is limited to self-report data of the schools and no direct indication is provided about differences in student outcome depending on the type of school, ASD-specific educational adaptations are considered to be worth the effort since previous research has demonstrated that these adaptations result in improved student outcome (Panerai et al., 2002). However, interviews with key professionals in special schools have revealed that these educational adaptations require extra funding and attention. Many schools have to distribute their financial resources unevenly between classes with and without students with ASD to the advantage of the ASD-specific classes, since the education of students with ASD makes great demands on the staff as far as training, endurance, and acquiring specialized instructional techniques are concerned. Besides, properly adapted education of students with ASD does not only have an impact on the classes involved, but on the school in its entirety. All this implies that the organization of ASD-specific education is a challenge, affecting staffing levels and infrastructure. Despite the efforts that the schools in Flanders make to optimize their education for students with ASD, the analyses of the questionnaires and the interviews show that in many schools the ASD-specific adaptations could be improved. Additional financial and infrastructural resources seem to be a major factor in improving ASD-specific education. Considering the increased prevalence of children with ASD within the normal range of intelligence (Chakrabarti & Fombonne, 2001) and since general education schools apparently try hard to adapt their education to the needs of students with ASD, more attention must be paid to extra funding and the organization of extra support for students with ASD and their teachers in general education schools. Nevertheless, general education for all students with ASD seems to be unrealistic at the present, given the current unfavourable economic climate that limits the resources for fully adapting general education to the extensive and unique needs that children with ASD have. Consequently, the importance of continuing the training and development of special schools with ASD-specific education should not be underestimated. Although more than half of the special schools where students with ASD are enrolled do not have an adjusted programme for children with ASD, it would be unwise to invest in extending ASD-specific education to all special schools. But in

special schools without an ASD-specific approach the organization of ASD-specific training is of major importance, 1) as especially these schools fulfil an important role in detecting students with ASD, and 2) to be able to have some consideration for the special needs of children with a suspected ASD (possibly in anticipation of specialized education in an adjusted class).

Finally, we would like to emphasize that the best educational environment for students with ASD has to be assessed individually and is not connected with a single classroom model. Although the least restrictive environment is often associated with an inclusive environment, we are convinced that an individualized, skill-oriented, and predictable environment will be the least restrictive environment for many students with ASD, because these adaptations often imply a life with more independence, less behavioural problems, fewer errors (Panerai et al., 2002), and as a result a better quality of life.

CHAPTER 2

SERVICE PROVISION FOR PERSONS WITH AUTISM SPECTRUM DISORDER IN FLANDERS

ABSTRACT

The aim of the present study was to acquire an overview of the quality and accessibility of the current service provisions for persons with autism spectrum disorder (ASD) in Flanders (Belgium). The study gathered data from questionnaires administered to 352 services for persons with disabilities and from interviews conducted in 18 services with a broad expertise in ASD-specific interventions. The results revealed that the prevalence of an ASD-specific intervention approach in the services was not common. Moreover, only half of the services supporting clients with ASD reported adjusting the goals, interventions, and evaluation criteria to the specific needs of these clients. Furthermore, components of effective practices for persons with ASD were strongly related to the number of clients with ASD supported by the service. Finally, significant problems with respect to accessibility of the services for persons with ASD were mentioned. The practical implications of these research findings are discussed.

INTRODUCTION

Autistic disorder is described in DSM IV-TR as a pervasive developmental disorder, characterized by qualitative impairments in three core symptom domains: social interaction, communication, and restricted, stereotyped patterns of behaviour, interests, and activities (American Psychiatric Association, 2000). In addition to autistic disorder, two other specific diagnoses are included within the category of pervasive developmental disorders (which are often called autism spectrum disorders or ASDs): Asperger's Disorder and Pervasive Developmental Disorder - Not Otherwise Specified. These two disorders are related to autistic disorder but differ with respect to number or type of symptoms associated with it. The prevalence of ASD is often estimated around 30/10,000, but more recent surveys suggest that ASD affects between 60 and 70 per 10,000 life births (Fombonne, 2003). This increasing prevalence of ASD has relevance for the provision of services. Considering the significance of effective support for persons with ASD throughout the lifespan (Corsello, 2005; Howlin, 1997; Renty & Roeyers, 2005a, see Chapter 1; Tantam, 2003), it is of the utmost importance that services respond in accordance to the increasing prevalence of ASD and make efforts to provide adapted support. Many aspects of interventions and programs relevant to other children or adults (with or without disabilities) are useful for persons with ASD. As for all persons, interventions must be individualized and tailored to the specific needs, strengths, weaknesses, and preferences of the individual person. In addition, persons with ASD often present very specific challenges for intervention (National Research Council, 2001). The literature regarding ASD-specific interventions and programmes has expanded enormously in the last 10 to 20 years (Dawson & Watling, 2000; Howlin, 1998). Although there has been a substantial body of sound research on interventions for persons with ASD, research conducted so far has failed to identify one single mode of intervention that is likely to be effective for all persons with ASD. Rather, documented support exists for several essential components of effective practices, mainly regarding young children with ASD. Review studies (Howlin, 1998; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999; Iovannone, Dunlap, Huber, & Kincaid, 2003; National Research Council, 2001) recognize the importance of the following elements of interventions for persons with ASD: the individualization of support, a

specialized curriculum, a supportive and comprehensible environment, family involvement, and highly trained staff.

Firstly, since ASD is not a single condition but rather a spectrum of disorders with a wide heterogeneity of presentations, individualization is essential. Iovannone et al. (2003) identified three basic characteristics of individualized support: 1) the person with ASD's preferences and special interests are incorporated in the intervention, 2) the family's preferences are taken into account when determining goals and methods, and 3) the intervention focuses on the person's strengths and weaknesses to determine the most appropriate intensity and level of instruction to meet the person's individual goals. Optimal progress of a person with ASD is considered as a function of the extent to which assessments of the person's abilities and the selection of interventions are individualized.

A second component of effective interventions that researchers have identified is the specialized curriculum. Hurth et al. (1999) stated that, besides instructional needs that persons with ASD share with other persons, there are developmental characteristics that are specific to ASD: the development and use of language, the development of social interaction skills, and the restricted interests and repetitive behaviors. Specialized curricula should therefore include systematic instruction in social and engagement skills, appropriate recreation or leisure skills, language comprehension and communication, and learning to attend to elements of the environment and context (Hurth et al., 1999; Olley, 1999).

Further, a supportive and comprehensible environment has been identified as another component of effective practices for persons with ASD. This means that the environment, the materials, and learning interactions are organized in such way that the acquisition of specific skills is elicited, facilitated, or supported (Hurth et al., 1999). These arrangements include for instance the use of visual cues. A comprehensible environment facilitates predictability for persons with ASD and enables them to anticipate to requirements of specific settings (Gresham, Beebe-Frankenberger, & MacMillan, 1999).

The fourth component concerns the importance of family involvement. Charman and Baird (2002) stated that it is critical that parents accept and

understand the diagnosis of their child with ASD and that they are able to manage and to attune to their child's individual needs. Alongside the provision of advice and support to parents, it is important that ongoing exchange takes place about how best to understand the individual's development and support needs. Since persons with ASD generally show deficits in their ability to generalize, a collaborative partnership with the social network can contribute to the effectiveness of interventions (Iovannone et al., 2003).

Finally, training in ASD has been considered as a key factor in the development and maintenance of good support (Peeters, 2000). Extensive training and experience in ASD-specific interventions enable professionals to fully understand the specific needs of the person with ASD and to adapt the environment and communication style to his or her needs. The National Research Council (2001) stated that it is unlikely that similar outcomes could be achieved if expertise in ASD is not readily available.

Apparently, the primary focus of research reviews has been the identification of essential components of effective intervention programmes. However, information on service delivery and the extent to which the aforementioned components of effective interventions for persons with ASD occur, is generally lacking. Nevertheless, this quantitative information on services is valuable for planning. It both increases our understanding of current practice patterns and informs the debate on training needs and future supply of services.

The Flemish situation

In Flanders, no public provisions for persons with disabilities were established until 1876. Until then, persons with disabilities were mainly educated and supported in charitable centres, which were often under auspices of the church and the Catholic clergy. In 1876 a special Community Fund was founded, which enabled the local authorities to establish public institutions that provided maintenance and care for people with support needs. After the second World War, a system of social security was drawn up, as well as the legal, financial, and administrative foundation for service provision for persons with disabilities. At

present, support for persons with disabilities comes under the Flemish Fund for Social Integration of Persons with Disabilities. This ‘Flemish fund’ provides (financial) grants to persons with disabilities on an individual base and subsidizes (both inpatient and outpatient) services for persons with disabilities all over Flanders. The subsidies services receive depend on the type of the service (e.g., outpatient vs. inpatient) and on the number of persons with disabilities supported by the service.

In particular, with respect to persons with ASD, Flanders has approximately 20 years history in autism-specific education and support (Peeters, 2000). Despite the extensive opportunities to follow ASD-specific training in Flanders, a previous study in Flemish special schools revealed that less than half of the special schools which educate children with ASD adapt their programme to the needs of these students (Renty & Roeyers, 2005a). The prevalence of ASD-specific support in service provisions is less clear until now.

The primary focus of this study was to acquire an overview of current service supply for persons with ASD and of the extent to which the essential components of effective practices occur in Flemish inpatient and outpatient services for persons with disabilities.

METHOD

Instruments and procedure

Two methods were used: questionnaires and semi-structured interviews. The former method was chosen to gain an overview of the current service supply for persons with ASD in Flanders at the present time. This method enabled us to sample a broad group of services, which was a prerequisite to answer the research question. The interviews were used to gain more in-depth knowledge about the characteristics of the support provided by services with an ASD-specific approach.

Based upon existing literature on service evaluation (Nesbitt, 2000; Sperry, Whaley, Shaw, & Brame, 1999), a postal questionnaire survey was compiled for the purpose of this study. Six main domains were covered: general information about the service (e.g., service type, waiting list, capacity, number of clients with ASD), information about ‘programme and interventions’ (e.g., assessment, therapy, environmental adaptations), ‘involvement of the parents’ (e.g., type and frequency of contact), ‘general knowledge and training about ASD’ (e.g., level of ASD-specific knowledge, type and frequency of ASD-specific training), ‘contact with other services’ (e.g., cooperation, referrals), and ‘future needs and expectations’. The questionnaire was piloted in eight services for people with disabilities. The coordinators responsible for ASD-specific interventions within the service were asked to complete the questionnaire and to comment on the design. This involved taking into account the clarity and relevance of the questions, the comprehensiveness of the multiple-choice answers and the time it took to complete the entire questionnaire. The questionnaire was amended corresponding the comments of these coordinators.

The data gathered from the questionnaires were supplemented with information obtained from interviews we carried out with the coordinators responsible for ASD-specific interventions within the service. These interviews enabled us to explore the organization of interventions for persons with ASD more in depth, as well as the perceived strengths and weaknesses of Flanders’ service provision for persons with ASD. The same topics as the ones in the questionnaire were discussed. The 18 interviews, each lasting about an hour and a half, were audio-recorded and later transcribed verbatim. The data obtained from the interviews were analyzed for common themes by means of MAXqda (VERBI Software, 2001; Berlin, Germany). In the results section of this paper, illustrative quotations are provided, followed by a service number. These quotations, selected for their relevance to the themes, enable the reader to judge the interpretations of the authors.

Participating services

All inpatient (residential) services and outpatient services (e.g., rehabilitation, day treatment, home based treatment) for people with a disability ($n = 560$) in Flanders (Dutch speaking part of Belgium) received the questionnaire by mail. Almost two thirds of the services ($n = 352$) participated in the study.

A drop out analysis was carried out by telephone within a random sample of 39 services that did not return the questionnaire. During the telephone call we inquired about the number of persons with a diagnosis of ASD in the service. The percentage of services with clients with a formal diagnosis of ASD was 60% and 58% in the participating and non-participating services respectively ($\chi^2(1) = 0.136$, $p = .418$). The consideration that maybe only services with clients with ASD would be likely to fill in the questionnaire, was falsified.

Given the focus of this study on the service provision for persons with ASD, the analyses were merely conducted on the data from the services in which clients with a formally diagnosed ASD were registered. Consequently 40% of services ($n = 139$) were excluded from further analyses since they did not support clients with ASD.

The final set of services included in the analysis consisted of 118 inpatient and 95 outpatient services. Table 1 displays the average number of clients registered in the participating inpatient and outpatient services, as well as the average number of clients with a diagnosed or suspected ASD.

Table 1
Average size of the total service population and average number of clients with diagnosis of ASD or suspected ASD in inpatient and outpatient services

	Inpatient services <i>M (SD)</i>	Outpatient services <i>M (SD)</i>
Size of total service population	85.24 (75.39)	157.71 (200.39)
Clients with ASD	12.60 (19.53)	14.33 (31.67)
Clients with suspected ASD	3.39 (5.19)	3.22(4.75)

The sample for the second method used in this study, the interviews, consisted of 18 services. Two general inclusion criteria were put forward to select the services that would be eligible to participate in the interviews: firstly, the services had to mention that they adapt their programme to the specific support needs of individuals with ASD, and secondly, more than 10% of the clients had to be diagnosed with ASD. The sample was stratified across region, service type (inpatient/outpatient), and population size.

RESULTS

The prevalence of essential components of effective support

Individualization of support

Approximately half of the services (52%) reported that the program of each client with ASD within the service is individualized. Chi-squared comparisons showed a statistically significant difference between inpatient and outpatient services for individualization, with outpatient services being significantly more associated with an individualized program than inpatient services ($\chi^2(1) = 6.63, p = .007$). Besides, the number of clients with ASD registered in the services was significantly different for services with and without an individualized program (M individualization = 16.64, M no individualization = 7.72, $F(1,200) = 6.70, p = .010$).

Half of the services (49%) mentioned having an ASD-specific approach in their service. This means that these services adjust their goals, support, and evaluation criteria to the impairments that are characteristic for ASD. Chi-squared comparisons showed no statistically significant differences between inpatient and outpatient services for the presence of an ASD-specific approach. The number of clients with ASD was significantly larger in services with an ASD-specific approach in comparison with services without ASD specific-approach (M with = 21.51, M without = 5.02, $F(1,211) = 24.91, p = .000$).

No significant differences were found for size of the total service population in services with and without an individualized program on the one hand and in services with and without an ASD-specific approach on the other hand.

Specialized curriculum

The participating services indicated the extent to which they provide a specialized curriculum for persons with ASD by reporting which of the following areas are a regular part of their curriculum: reduction of problem behaviour by a functional assessment of behaviour, instruction in social and engagement skills, training in appropriate recreation or leisure skills, and in language comprehension and communication. Table 2 shows the presence of each of these curriculum areas.

Except for the presence of training in leisure skills, no group differences were found between inpatient and outpatient services for the presence of each specific curriculum area.

Table 2
Occurrence of special areas as a regular part of the curriculum for persons with ASD in inpatient and outpatient services

	Inpatient services %	Outpatient services %	$\chi^2(1)$	<i>p</i>
Reduction of problem behaviour	40	35	0.43	.662
Social and engagement skills training	26	36	2.49	.122
Training in leisure skills	10	36	19.40	.000
Training in language comprehension and communication	39	50	2.43	.148

In a next step, differences between the number of clients with ASD in services with and without a specialized curriculum for persons with ASD were examined. No significant differences were found in the number of persons with

ASD between services who did and services who did not use a functional assessment of problem behaviour. On the contrary, we did find a significant difference for the number of clients with ASD in services which trained language comprehension and communication in comparison to services which did not (M with = 16.32, M without = 9.36, $F(1,200) = 3.96$, $p = .048$). A trend was found for differences in the number of students with ASD in services with and without training in leisure skills (M with = 18.88, M without = 10.59, $F(1,200) = 3.84$, $p = .052$) and in services with and without social and engagement skills training (M with = 16.68, M without = 10.40, $F(1,200) = 2.81$, $p = .095$).

A supportive and comprehensible environment

Table 3 demonstrates the extent to which respectively inpatient and outpatient services adapt their communication and environment to the needs of persons with ASD. Chi squared comparisons revealed that the use of alternative communication modes (e.g., day schedule, PECs, pictures, objects) is significantly more associated with inpatient than with outpatient services.

Table 3
Extent to which inpatient and outpatient services adapt communication and environment to the needs of clients with ASD

	Inpatient services %	Outpatient services %	$\chi^2(1)$	p
Adaptations in the living room	58			
Adaptations in the bedroom	39			
Adaptations in the workspace	62	59	0.21	.665
Use of alternative communication modes	90	72	10.62	.002
Use of task analyses	48	39	1.87	.199
Use of specially designed materials	46	42	0.26	.669
Use of adapted media	30	25	0.64	.526

Associations between number of clients with ASD registered in the service and the characteristics of a supportive and comprehensible environment were explored using ANOVAs. The analyses showed that the number of clients with ASD is significantly larger if the service adapts the environment to the needs of persons with ASD by means of the use of alternative communication modes ($F(1,200) = 4.10, p = .044$), the use of task analyses ($F(1,200) = 21.41, p = .000$), adaptations in workspace ($F(1,194) = 7.68, p = .006$), adaptations in living room ($F(1,194) = 19.00, p = .000$), adaptations in bedroom ($F(1,200) = 40.42, p = .000$), the use of specially designed materials ($F(1,200) = 20.12, p = .000$), and the use of adapted media ($F(1,199) = 19.92, p = .000$).

Parental involvement

Each domain of parental involvement was measured on a 5-point Likert-scale. Table 4 shows the extent to which the parents of the client with ASD are involved in the inpatient and outpatient services.

Table 4
Extent to which parents are involved in the inpatient and outpatient services

	Inpatient services <i>M (SD)</i>	Outpatient services <i>M (SD)</i>	<i>df</i>	<i>F</i>	<i>p</i>
Advice provided to parents	3.24 (.95)	3.20 (1.27)	1,191	0.80	.373
Parental involvement in development of IEP	3.18 (1.03)	3.19 (1.02)	1,191	0.00	.963
Written communication between parents and professionals	2.86 (1.62)	3.01 (1.79)	1,193	0.37	.546
Parental participation in activities of the service	1.50 (.75)	1.36 (.63)	1,181	1.72	.191
Parent to parent support groups	1.35 (.67)	1.37 (.77)	1,194	0.03	.865

The average number of clients with ASD was significantly associated with the extent to which the parents received advice from the service ($r = .252, p = .000$), the extent to which the parents were involved in the development of the Individual Education Plan ($r = .209, p = .000$), and the extent to which the service organized parent-to-parent support ($r = .255, p = .000$). For the written communication between parents and professionals, and for participation in activities of the service no significant association was found with the number of clients with ASD registered in the service.

ASD-specific knowledge and training

The percentage of services reporting that the staff members are given the opportunity to follow training about ASD, was similar for both inpatient and outpatient services (90% and 85%). Correspondingly, no significant difference was found between the two groups for autism-specific knowledge of the staff. The staff's knowledge was measured on a 5-point Likert scale over 5 categories: a) causes and prevalence of ASD, b) diagnostics of ASD and appropriate diagnostic instruments, c) assessment in persons with ASD, d) appropriate support for persons with ASD, and e) the prognosis of ASD. The average scores on autism-specific knowledge in inpatient and outpatient services was highest for the psychologists/pedagogues (M inpatient = 3.67, M outpatient = 3.78) and lowest for the care staff (M inpatient = 2.76, M outpatient = 2.92) and the manager of the service (M inpatient = 2.97, M outpatient = 2.73). The average scores of the paramedics were 3.05 for the inpatient and 3.33 for the outpatient services. The number of clients with ASD was significantly larger in services which organized ASD-specific training ($F(1,209) = 4.84, p = .029$). Furthermore, a significant association was found between the number of clients with ASD and the ASD-specific knowledge of the manager of the service ($r = .265, p = .000$), the psychologists/pedagogues ($r = .316, p = .000$), the care staff ($r = .309, p = .000$), and the paramedics ($r = .253, p = .003$).

Satisfaction and future needs

All services were asked to rate the quality of their support for persons with ASD on a 10-point scale, with higher scores on the scale reflecting better support for clients with ASD. The average scores of the inpatient and outpatient services were similar (M inpatient = 5.71 and M outpatient = 5.75). The quality score correlated significantly with the number of clients with ASD registered in the service ($r = .356, p = .000$).

Subsequently, the services were given a list of 5 resources that services may need to optimize their support for persons with ASD. The participants were asked to rank these 5 resources in order of importance for their service. Services that mentioned to have an ASD-specific approach were compared with services without ASD-specific interventions (see Table 5).

Table 5
Desired resources for the optimization of support for clients with ASD

Rank	Services with ASD-specific approach	Services without ASD specific approach
1	More staff	More training opportunities
2	More financial resources	More staff
3	Better infrastructure	More financial resources
4	More training opportunities	Better infrastructure
5	More adapted materials	More adapted materials

Accessing services for persons with ASD

Almost three quarters of the services (70%) mentioned that they are seldom or never able to refer a client with ASD to an appropriate school or service when necessary. In 79% of the cases this is due to the waiting lists.

Correspondingly, the majority of the inpatient (58%) and outpatient services (80%) that participated in our study reported to have a waiting list. The length of the waiting list was significantly smaller in inpatient than in outpatient

services (M inpatient = 11.51, M outpatient = 26.59, $F(1,211) = 11.97$, $p = .001$). The number of persons with ASD waiting for support was similar in inpatient and in outpatient services (M inpatient = 2.54, M outpatient = 2.83). The number of clients with ASD in the services is significantly associated with the length of the waiting list ($r = .423$, $p = .000$) and the number of persons with ASD on the waiting list ($r = .763$, $p = .000$).

In depth exploration of the organization of ASD-specific interventions and strengths and weaknesses of Flanders' service provision for persons with ASD

ASD-specific adaptations in the service

During the interviews, the services were asked to identify the components that characterize the specificity of the interventions and support for persons with ASD in the service. The main components quoted by the services were: individualization, empathy with the person with ASD, adaptations in communication, adaptations concerning the infrastructure, and the intensity of support.

'The most important thing is that the staff constantly must try to empathize with the person with ASD in order to clarify situations, communication, and expectations. Consequently, support needs to be individualized for persons with ASD. We have to take the unique needs of the individual person into account. In our service, we consciously do not try to be stuck in a fixed day structure, but we rather try to encourage a lot of variation in day planning. This enables the person with ASD to learn to be flexible when situations change. But it is very important to clarify situations and expectations by means of Picture Exchange Communication Systems and other alternative communication means.' (Service 1)

'There are less children in the ASD-specific groups. This enables the staff to work on a more individual basis with the child. The support for children with ASD is not only more individualized, it is also much more intensive. Things that are more or less natural for other children (e.g., meals,

playtime), are sometimes very difficult for children with ASD and have to be supported very intensively and on an individual basis. Consequently, in the ASD-specific groups there is much more staff than in the other groups for children with intellectual disabilities.’ (Service 7)

‘We have tried to clarify the physical environment in such a way that all places have become a distinct and unambiguous entity with a clear function. For instance meals and leisure time activities take place at another table, doors are clearly marked with visual symbols, the clients with ASD have their own place, etc.’ (Service 11)

Staff, ASD-specific knowledge, and training

The interviews revealed that new staff members had received very limited information about ASD during their education. Consequently, extra training in ASD, organized by the service, is very common. Some services mentioned to be absolutely convinced that supervised hands-on experience is far more important for new staff members than sharing information through didactics (e.g., lectures, readings).

In general, the services are very satisfied with the supply of training about ASD in Flanders. There are enough workshops, congresses, symposia, etc., both with theoretical and practical information about ASD and ASD-specific interventions. However, many services mentioned the lack of training about the comorbidity of ASD and intellectual disability.

‘Unfortunately, congresses and workshops tend to focus on high functioning persons with ASD. Our clients with ASD have severe intellectual disabilities, so it is very difficult to find information that suits our training needs.’ (Service 2)

Involvement of the parents

The services were asked about the role they ascribe to the parents of their clients with ASD. Almost all services underlined the importance of a close collaboration with the parents of the clients with ASD, both for the benefit of the person with ASD and for the benefit of his or her parents. Although most services stressed the fact that the service had a supportive function on behalf of the parents, rather than a replacement function, some services reported that parents were merely invited to make decisions about their child, as long as this was compatible with the general interest of the ASD-specific group where their child lived.

'In our service we try to start from the basic principle of shared responsibility with the parents, but we are always considerate of the abilities and limitations of the parents because some parents have to cope with lots of stressors. We perceive the collaboration with the parents as a partnership with equal partners.' (Service 7)

Strengths of Flanders' service provision for persons with ASD

The services identified the fact that there are many training opportunities about ASD as the major strength concerning service provision for persons with ASD in Flanders. The education centres specialized in ASD-specific training are highly esteemed both for their extensive training supply and for their expert advice concerning the organization of ASD-specific support for persons with ASD in practice.

Weaknesses of Flanders' service provision for persons with ASD

The main weaknesses identified by the services were the long waiting lists and the lack of extra funding, staff, and infrastructure for services that support persons with ASD. Given the points of special interest with regard to interventions for persons with ASD (e.g., individualization, adaptations in communication and environment, more intensive support, training needs of the staff), the organization of ASD-specific support requires more resources (e.g., staff, infrastructure) than

the organization of other interventions. Some services mentioned that, as a result of shortage of staff, they follow very strict criteria to admit new clients to their service. For instance, persons with ASD with high levels of challenging behaviour or persons who need high intensity of support may not be admitted to the service because of a lack of resources to support this person. For services that support persons with ASD, the solution lies in the linking of granted subsidies to the level of support intensity that the person requires.

DISCUSSION

The purpose of the present study was to describe the service provision for persons with ASD in Flanders, by examining the extent to which essential components of effective practices occur in both inpatient and outpatient services. Previous research identified several essential components of effective interventions for persons with ASD (Howlin, 1998; Hurth et al., 1999; Iovannone et al., 2003): individualization of support, a specialized curriculum, a supportive and comprehensible environment, family involvement, and highly trained staff. Despite the fact that all services included in the analysis supported one or more persons with ASD, the results revealed that the presence of an ASD-specific approach in the service was not common. In point of fact, only half of the services reported to adjust the goals, support, and evaluation criteria to the impairments that are characteristic of ASD. Examining the core components of effective practices in more detail, the present study revealed that the occurrence of individualization, a specialized curriculum, and a supportive and comprehensible environment (except for the use of alternative communication and adaptations in workspace and living room) were rather low (about half or less of the services). The extent to which the parents were involved in the services was moderate. Opposite that, the percentage of services reporting that staff members were given the opportunity to follow ASD-specific training was very high.

Next to the above-mentioned prevalence of ASD-specific components in Flemish services, three specific findings warrant further attention. Firstly, the presence of ASD-specific components of intervention was for the most part similar

for inpatient and outpatient services, with the exception of the use of an individualized approach, the use of alternative communication, and training in leisure skills. These three exceptions are probably more connected with the kind of support that is offered in the respective services, than with the fact that one service type makes less effort to adapt the program to the needs of clients with ASD as compared to the other one (e.g., the fact that individualization occurs more frequently in outpatient services might be due to the individual approach that many outpatient services (e.g., rehabilitation centers) have).

Secondly, our results demonstrated the significance of the number of clients with ASD in the service. It is remarkable that almost all core components of effective practices were strongly related to the number of clients with ASD. Given the cross-sectional nature of the present study it is not clear whether the presence of ASD-specific support attracts more clients with ASD or whether the presence of more clients with ASD rather paves the way for specialization.

Thirdly, with respect to the accessibility of services for persons with ASD, significant problems were mentioned. The majority of the services has a waiting list and the number of clients with ASD on these waiting lists is significantly associated with the number of clients with ASD registered in the service. This finding lends evidence for the fact that specialized services attract more clients with ASD. Furthermore, the interviews revealed that mainly referrals for persons with ASD and high levels of challenging behaviour or for persons who are in need of a high intensity of support, are problematic.

A number of sampling and methodological issues in this study warrant some precautions in the interpretation of the data. Firstly, the data relied on services opting to participate in the study and thus it is possible that the sample is not representative of the group of Flemish services for persons with disabilities as a whole. Although the drop out analysis failed to find a difference between participating and non-participating services with respect to the presence of persons with ASD in the service, it is still possible that both groups differ on other variables, such as size of the service, extent of ASD-specific adaptations, ASD-specific knowledge of the staff, etc. Secondly, the collection of the data relied on self-report measures only. Therefore, it is possible that the data are biased due to

social desirability. Furthermore, since we had no information about the specific support needs of the clients with ASD, it was not possible to assess the extent to which the interventions were tuned to the unique support needs of each individual with ASD within the service. However, the major part of the information gathered in the present study represents rather general features of effective interventions that are important for all persons with ASD (e.g., individualization).

Despite the above-mentioned limitations, we are convinced that the present study has some very important practical implications. Firstly, in consideration of the support intensity, the importance of individualization, and the possible requirements regarding infrastructure for persons with ASD (Van Bourgondien & Elgar, 1990), it is obvious that paying attention to the essential components of effective practices demands extra resources, both on the level of staffing and infrastructure. Services that exert themselves to adapt the interventions to the special support needs of persons with ASD frequently mentioned a lack of financial resources to invest in personnel, training, infrastructure, and materials as needed. Currently, the amount of subsidies depends on the type of service and the number of clients supported by the service. Instead of this subsidy practice, a linking between the amount of subsidies services receive and the intensity of support clients need, would be a better solution for services that support persons with more intensive support needs. Although this linking would strengthen the supporting power of services with clients with higher support needs in general, it certainly would give room to the optimization of different components of effective ASD-specific interventions. Furthermore, this linking possibly could result in a reduction of waiting lists for persons with ASD as some services have now established strict admission criteria to keep guard over the staffing, the infrastructural resources, and the supporting power they have.

Secondly, our results demonstrated that the presence of effective practices for persons with ASD is highly associated with the number of clients with ASD registered in the service. A better distribution of clients with ASD over different services would on the one hand enlarge the total number of skilled staff needed, but might on the other hand decrease the chance that staff would lose important skills (e.g., that they would give up talking to clients with ASD who have poor communication skills) (Mansell, Ashman, Macdonald, & Beadle-Brown, 2002).

However, the introduction of ASD-specific training in the basic curriculum of future service staff may increase the number of skilled staff, which may in turn result in more services qualified for supporting persons with ASD. Although the services identified the ASD-specific training facilities as a major strength in Flanders, the ASD-specific knowledge of the care staff is in the present study estimated as being below the average of the 5-point scale. Besides, the interviews revealed that the knowledge of new staff about general features of ASD and about appropriate support for persons with ASD is generally very low. Given the importance of training as a key factor in the optimization of effective support for persons with ASD (Peeters, 2000), consideration needs to be given to ensuring that ASD-specific training is included in both the basic curriculum of students, in in-service training for newcomers, and in continuing professional development of the staff.

Finally, the findings of the present study indicate that, although the services themselves recognize the importance of a close collaboration with the parents of the client with ASD, the actual parental involvement was rather moderate. The scores on the 5-point Likert scales about parental involvement were rather low and during the interviews, parental involvement was not quoted by the services when they were asked to identify the major cornerstones of the ASD-specific interventions and support provided by the service. Nonetheless, several authors stressed the importance of parental involvement since sound collaboration between parents and professionals would markedly improve the consistency of support interventions and would help to ensure generalization and maintenance of newly acquired behaviors (Charman & Baird, 2002; Dunlap, 1999; Howlin, 1998). Therefore, it might be important to strengthen the involvement of the parents in the future, under the condition that the optimal level of participation is determined based upon the family characteristics, stressors affecting the family, and the needs of the individual with ASD.

Part II

SUPPORT NEEDS AND EXPERIENCES OF PERSONS WITH AUTISM SPECTRUM DISORDER

CHAPTER 3

SATISFACTION WITH FORMAL SUPPORT AND EDUCATION FOR CHILDREN WITH AUTISM SPECTRUM DISORDER: THE VOICES OF THE PARENTS¹

ABSTRACT

The aim of the present study was to identify and describe factors associated with variations in the level of parental satisfaction with formal support and education for children with autism spectrum disorder (ASD) in Flanders. Participants were recruited by a mailing from a diagnostic centre for preschoolers and by advertisements dispersed in the Flemish parent organization for ASD and in services and special schools. The sample consisted of 244 parents of children with ASD (age range: 2.69 – 17.81 years, male:female sex ratio 1:4). The data were collected using a questionnaire about experiences with education and support, which was compiled for the purpose of this study. The data resulting from the questionnaire were supplemented with information obtained from semi-structured in-depth interviews with a stratified sample of 15 parents. The study revealed that parents experienced difficulties with the diagnostic process, with support and education provided by mainstream settings, and with the accessibility of autism-specific service provisions. Conversely, parents reported to be satisfied with the quality of autism-specific support and education. Predictors of overall satisfaction were parental involvement in formal support, knowledge of available service provisions, and time between first consultation and final diagnosis. Practical implications of the results are discussed.

¹ Renty, J., & Roeyers, H. (in press). Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents. *Child: Care, Health, and Development*.

INTRODUCTION

There have been a lot of reports in the literature about the importance of social support in individual, interpersonal, and family functioning in families of children with a disability (e.g., Dunst, Trivette, Hamby, & Pollock, 1990; Kwai-sang Yau & Li-Tsang, 1999; White & Hastings, 2004). According to the double ABCX model (McCubbin & Patterson, 1993), available support may act as a buffer against the demands of caring for a child with a disability, resulting in better family adaptation. Particularly, the role of informal social support has been established (White & Hastings, 2004). Different sources of informal social support in families of children with a disability are expected to influence personal, family and child functioning. Firstly, several studies have demonstrated that support within the nuclear family correlates with lower stress levels in parents of children with a disability (Johnston et al., 2003). In particular spousal support is considered to be an important factor in adaptation for both mothers and fathers (Snowdon, Cameron, & Dunham, 1994). Secondly, support from the extended family (e.g., grandparents) is associated with reduced stress in the parents of children with a disability (Trute, 2003). Grandparents are likely to be an important source of support for families with children with a disability, even if they live some distance away (Hastings, Thomas, & Delwiche, 2002). Thirdly, other sources of informal support, such as friends, neighbours, volunteers, religious groups, etc. may help parents to cope with the demands of caring for a child with a disability (Trivette & Dunst, 1992).

The role of formal support from statutory services in reducing stress levels of parents of children with a disability is less clear. Formal support from professionals and services has less significance in terms of stress reduction than informal support from the personal social network. In particular, several studies have revealed that, in many cases, families of children with a disability did not receive useful support tuned to their needs or those of the individual child (Florian & Krulik, 1991; Sloper & Turner, 1992). Nevertheless, parents consider help and support from professionals to be very important (Taanila, Syrjälä, Kokkonen, & Järvelin, 2002). Professional support can play an important role in providing information, in training parents in effective problem-solving, in relieving the

parents of the daily demands of their disabled child, and in developing linkages among families as well as between families and services. The contribution of professional support, in conjunction with informal support from the social network, could be very important in families of a child with a disability, under the condition that this professional support is appropriate. Therefore, it is of the utmost importance to tune professional support to the needs of the families of a child with a disability. The first step in optimizing professional support is the evaluation of experiences of service users and the exploration of their needs. The views of these most important stakeholders could then be used to inform policy makers, professionals, parents, and persons with a disability in the development towards better services and support systems. The significance of parental satisfaction as an indicator for the effectiveness of intervention programmes has been recognized by many researchers (e.g., Boyd & Corley, 2001; Hancock & Kaiser, 2001; Mesibov, 1997).

In contrast to these studies which mainly concentrate on the evaluation of particular intervention programmes, the purpose of the current study is to evaluate parents' satisfaction with the accessibility and quality of education and support for their child with autism spectrum disorder (ASD) in general. Autism is characterized by severe qualitative impairments in social interaction and communication and restricted, stereotyped patterns of behaviour, activities, and interests (DSM IV-TR; American Psychiatric Association [APA], 2000). The autism spectrum consists of autism and related disorders, such as Asperger's Disorder and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) (Wing, 1996). The nature of ASD involves the need for an adjusted approach, in which particular attention is paid to clearness, continuity, and predictability. Research indicates that ASD-specific intervention towards children with ASD shows positive outcomes (Panerai, Ferrante, & Zingale, 2002). However, appropriate support for persons with ASD requires specialist knowledge, training, and distribution of often scarce resources (Renty & Roeyers, 2005a; Sperry, Whaley, Shaw, & Brame, 1999). Previous research in the evaluation of services for persons with ASD has demonstrated shortcomings concerning 1) early identification, 2) information about available service provisions, 3) specialist knowledge about ASD, 4) cooperation between parents and professionals, and 5) the availability of appropriate support.

Firstly, concerning early identification, several studies demonstrated that the time and effort required to obtain a firm diagnosis of ASD are often considerable. Parents of children with ASD reported becoming concerned about their child's development at about 18 months and first seeking professional help or advice at about 24 months (De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Young, Brewer, & Pattison, 2003). Although symptoms are often recognized by the parents in early infancy, the average age of diagnosis has been reported as ranging from 3 ½ to 6 years (Howlin & Moore, 1997; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Young et al., 2003). The National Autism Plan for Children (NIASA, 2003) mentioned that the response of many professionals on the parents' first concerns often was an inappropriate reassurance or gave the impression that the parents were 'over anxious'. A study of Brogan and Knussen (2003) demonstrated that the length of time parents have to wait before obtaining a final diagnosis for their child was strongly related to parental satisfaction with the diagnostic process. Other determinants for parental satisfaction were: the age of diagnosis, the quality of information given during the disclosure interview, and the clarity or certainty of the final diagnosis given (parents are more satisfied when a clearcut or specific diagnosis (e.g., autism or Asperger's Disorder) was provided for the child's disability, rather than a diagnosis that referred more vaguely to autistic traits or tendencies) (Brogan & Knussen, 2003; Howlin & Moore, 1997).

Secondly, parents should be given more direct help and support in the early years of the child, in order to help them develop appropriate skills and strategies, which could impact current and later quality of life of the child (Howlin, 1997; NIASA, 2003). However, many parents and professionals report on the lack of available information about service provisions, such as appropriate education, social services, leisure services, health services, etc. and on how these services are accessed and organized (Nesbitt, 2000). These findings were confirmed in a study of Whitaker (2002) about autism-specific support for preschool children with autism, in which the need for more information about the available local educational and support options was expressed. In line with this, the NIASA (2003) recommended that families of children with ASD should have a key worker who supports the family, provides information about local services and training opportunities, coordinates transitional planning, etc.

Thirdly, several authors have demonstrated the crucial importance of knowledge of the features of ASD in establishing and maintaining good practice (Brogan & Knussen, 2003; NIASA, 2003; Peeters, 2000). The quality of life of an individual with ASD may largely depend on the way we adapt the environment to his or her needs. Training can be seen as a key factor in understanding how to meet these support needs of persons with ASD. However, many parents mentioned difficulties with the accessibility of proper information, referring to the overwhelming amount of information on the internet and the difficulty in determining its relevance and applicability to their own child with ASD (Nesbitt, 2000; Whitaker, 2002).

A fourth need concerns the cooperation between parents and professionals. The NIASA (2003) identified active family involvement as one of the key principles for the support of persons with ASD. Families tend to be more involved in the accomplishment of goals set for their children, if there exists a parent-professional partnership in which the family and professionals function collaboratively in the development of those goals (Bernheimer, Gallimore, & Weisner, 1990). However, in the past the relationship between parents and professionals has not always been characterized by a partnership. Many professionals acted in a paternalistic way when working with families of a child with a disability (Sperry et al., 1999).

Finally, concerning the availability of autism-specific support, parents experience problems in accessing specialist schools and services (Nesbitt, 2000). Notably, these accessibility problems occur much more frequently in services and schools with an ASD-specific approach. Reasons for that lie in their long waiting lists and in the fact that ASD-specific schools often require a formal diagnosis of ASD (which is difficult to obtain due to the long waiting lists in the diagnostic centres; Renty & Roeyers, 2005a).

The Flemish education and support system

Flanders has a well-developed network of special schools as an independent and specific form of education for students with various kinds of disabilities. Although there are 8 school types for special education in Flanders (designed in accordance with the target group), there is no particular school type for children with ASD. As a result, students with ASD are scattered over different types of special schools. Completely dependent on the motivation of the schools, some special schools retrain and apply for professional help to increase their expertise in educating students with ASD, while other special schools approach students with ASD the same way as students with any other disability (Renty & Roeyers, 2005a).

Besides this fully segregated form of education in special schools, the Flemish school system enables students with disabilities to attend a general education school, possibly with weekly 2 to 4 hours of support from a special school. Despite the fact that this – so-called – integrated education has been provided for by law since 1986, it is only during the last few years that students with ASD are actually applying for this form of support in general education schools.

Flanders has approximately 20 years history in autism-specific education and support (Peeters, 2000). Despite the extensive opportunities to follow ASD-specific training in Flanders, results of a recent study in Flanders' special schools revealed that only 44% of the special schools where children with ASD are registered confirm that they adapt the educational programme and environment to the needs of these students with ASD (Renty & Roeyers, 2005a). Notwithstanding the evidence that these ASD-specific adaptations result in improved student outcomes for many students with ASD (Panerai et al., 2002), little research has been conducted with respect to experiences and satisfaction of the parents of children with ASD.

The current study aims to identify the views of a sample of parents of children with ASD concerning their satisfaction and dissatisfaction with current support and education for their child.

METHODS

Participants

The sample for the survey was drawn from three sources. Firstly, about half of the participating parents ($n = 125$) was recruited through an advertisement in the journal of the Flemish parent organization for ASD. Secondly, 105 parents took part in the research at invitation of a diagnostic centre. This centre sent a mailing to all parents of children with ASD who were diagnosed at the respective centre in the last decade ($n = 180$). Finally, 14 participants were recruited through a mailing of 20 services and 10 special schools with facilities for children with ASD. To be eligible to participate in the study, respondents had to be parent or guardian of a child who was aged 18 or younger and who was diagnosed with ASD by an authorized multidisciplinary team. The final sample comprised 244 parents of children with ASD.

The survey was completed by 157 mothers (64%) and 18 fathers (7%). Sixty-one surveys were filled out by both parents (25%) and 8 by others (3%) (e.g., grandparents). The participating families had an average of 2.57 ($SD = 1.13$) children. In almost a fifth of the families there was another family member with a formally diagnosed ASD (19%) and 17% of the parents suspected that there is another family member with ASD. According to the Hollingshead Four Factor Index for socio-economic status (Hollingshead, 1975), there were 135 parents in Classes I-III (lower socio-economic classes) and 108 parents in Classes IV-V (upper socio-economic classes).

The children with ASD ranged in age from 2.69 years to 17.81 years, with an average of 8.87 years ($SD = 3.42$). The male:female sex ratio was 4:1. Of the 244 children with ASD, 85 (35%) had an intellectual disability, 58 (23%) children had emotional and behavioural problems, 17 (7%) were physically impaired and 3 (1%) had a sensory impairment.

Table 1
Description of the sample of children whose parents participated in the interviews

Interview number	Age (years)	Intellectual ability	Age of diagnosis (years)	Education	Support	Diagnosis	Presence of speech
1	4	Normal	2;10	General with support	Rehabilitation	Autistic Disorder	Yes
2	5	Severe ID	5;9	Special (not ASD-specific)	Home based treatment	ASD	No
3	8	Moderate ID	1;6	ASD-specific	Residential placement during the holidays	Autistic Disorder	No
4	8	Mild ID	7;2	ASD-specific	None	ASD	Yes
5	9	Mild ID	4;1	ASD-specific	Rehabilitation	ASD	Yes
6	9	Moderate ID	4;9	ASD-specific	Rehabilitation and home based treatment	PDD-NOS	Yes
7	10	Normal	9	Special (not ASD-specific)	None	ASD	Yes
8	11	Normal	4;6	General	None	ASD	No
9	11	Moderate ID	7	ASD-specific	Home based treatment	PDD-NOS	Yes
10	12	Normal	3;6	Special (not ASD-specific)	Rehabilitation	ASD	Yes
11	12	Severe ID	9;9	Special (not ASD-specific)	Home based treatment	ASD	No

Table 1 (continued)

Description of the sample of children whose parents participated in the interviews

Interview number	Age (years)	Intellectual ability	Age of diagnosis (years)	Education	Support	Diagnosis	Presence of speech
12	13	Moderate ID	1;10	ASD-specific	None	Autistic disorder	Yes
13	15	Normal	12	General	None	ASD	Yes
14	17	Normal	8	Special (not ASD-specific)	Residential placement	PDD-NOS	Yes
15	18	Normal	14;1	General with support	Psychiatrist	Asperger's Disorder	Yes

Note. ID, Intellectual disability

Measures

A survey was developed on the basis of a literature review about consumer satisfaction (Nesbitt, 2000; Sperry et al., 1999; Westling, 1996). The survey covered six main categories: general information about the family and the child with ASD (e.g., demographic and family characteristics, co-morbidity), information about the diagnostic process (e.g., age of diagnosis, first consultation, diagnostic centre, satisfaction), information about the accessibility of ASD-specific services and schools, information about received support and education (e.g., type, satisfaction, duration, involvement as parent, cooperation), information about autism-specific knowledge and training, and information regarding concerns and further needs.

The data resulting from the questionnaires were supplemented with information obtained from semi-structured in-depth interviews with a stratified sample of 15 parents of children with ASD. The sample was stratified by 7 child characteristics: age, intelligence, age of diagnosis, type of education, type of support, diagnostic label, and presence of speech. Table 1 describes the interviewed sample along these characteristics.

In the interviews, the same six categories of the survey were discussed and deepened. Prior to the interviews, the parents completed a consent form. The 15 interviews, each lasting about an hour, were audio-recorded and later transcribed verbatim. The data obtained from the interviews were thematically analysed to detect patterns of opinion with respect to each of the six categories of questions. In the results section of this paper, illustrative quotations of the respondents' views and experiences are provided, followed by a respondent number. These quotations, selected for their relevance to the themes, enable the reader to judge the interpretations of the authors.

RESULTS

The results of both the questionnaires and the interviews will be presented for each section of the questionnaire in the following sections.

Diagnosis

To avoid a misrepresentation of the results concerning the diagnosis, the surveys of the parents who were contacted by the diagnostic centre ($n = 105$) were excluded from the analyses. Furthermore, given the historical increase in the understanding of ASD and its diagnosis, higher ages of diagnosis can be expected in older children. Therefore, results concerning the diagnosis were subdivided into two groups: (a) children younger than 12 years ($n = 196$) and (b) children between 12 and 18 years ($n = 48$).

The parents were asked when they first sought professional advice concerning the problems of their child. In the youngest group (<12 years) this was at the average age of 3.53 years ($SD = 1.96$). The average age of the oldest group (>12 years) was 6.00 years ($SD = 3.53$). In the first group (<12 years), the diagnosis was not made until 2.12 years ($SD = 2.12$) after symptoms were recognized and until an average of 3.29 diagnostic centres ($SD = 1.76$) was consulted. In the meantime the child was 5.78 years ($SD = 2.41$) old. The oldest group of children (>12 years) obtained a diagnosis of ASD at the age of 10.51 years ($SD = 3.66$), after having consulted an average of 4.50 professionals ($SD = 2.94$) during 4.51 years ($SD = 3.71$). Table 2 and 3 respectively show which service was consulted when the first professional advice was sought and when the diagnosis was received.

Table 2
Professional with who parents first share concerns about the child's development

Professional seen	Children < 12 years (n = 99) %	Children > 12 years (n = 40) %
General practitioner	22	13
Paediatrician	19	28
School psychologist	27	30
Mental health care	4	5
Psychiatrist	7	15
Specialized outpatient clinic	9	3
Other	11	8

Table 3
Type of professional centre where diagnosis was obtained

Professional seen	Children < 12 years (n = 99) %	Children > 12 years (n = 40) %
Paediatrician	2	0
Rehabilitation centre	21	8
Child psychiatrist	13	20
Specialized outpatient clinic	58	53
Residential service for persons with a disability	1	3
Other	4	18

The parents were asked which labels were used by the diagnostic centre to communicate the diagnosis of their child. Overall, as Table 4 illustrates, clear and specific diagnoses (e.g., autism, Asperger's Disorder, ASD), were used more frequently than vaguer diagnoses, as for instance autistic tendencies.

Table 4
Diagnostic label used during the disclosure interview

Diagnostic label	Children < 12 years (<i>n</i> = 99) %	Children > 12 years (<i>n</i> = 40) %
Autism	21	21
Asperger's Disorder	20	26
ASD	58	39
PDD-NOS	10	23
Autistic tendencies	6	3
Atypical autism	10	3
Autism related disorder	8	3

When the diagnosis was communicated, 67% of the parents received information about ASD and 53% was informed about how ASD manifests itself in their child. Concerning appropriate support for the child with ASD, 41% of the parents received information about suitable services and schools and 35% was given advice about how to support a child with ASD. Sixty percent of the parents received a written diagnostic report.

Satisfaction with the diagnostic process was measured on a 5-point Likert scale (1 = *very dissatisfied*; 5 = *very satisfied*). Overall, about half of the parents (51%) was satisfied or very satisfied with the diagnostic process.

The relations amongst satisfaction with the diagnostic process and age of first consultation, number of consultations before diagnosis was obtained, age of diagnosis, and amount of information received after the diagnosis are displayed in Table 5. Overall, the pattern of correlations was as expected. Higher rates of satisfaction were related to lower age of diagnosis and more information after the diagnosis. Furthermore, a higher age of diagnosis was related to a higher age of first consultation and to a higher amount of consultations before diagnosis was obtained.

Table 5
Means, standard deviations (SD) and Pearson correlation coefficients (r) among satisfaction with the diagnostic process (measured on a 5-point Likert scale), age of first consultation (in years), number of consultations before diagnosis was obtained, age of diagnosis (in years) and amount of information received after the diagnosis (measured on a 5-point Likert scale)

Variable	Mean	SD	2	3	4	5
1. Satisfaction with diagnostic process	3.44	1.15	-.178	-.080	-.301*	.413*
2. Age of first consultation	4.28	2.77	-	-.006	.609*	.061
3. Number of consultations before diagnosis	3.64	2.23		-	.346*	-.048
4. Age of diagnosis	7.15	3.55			-	-.080
5. Amount of information after diagnosis	2.99	1.70				-

* $p < .01$

Note. The results in this table are based upon data from both <12 years and >12 years age groups together.

Congruently, the interviews revealed that parents who were dissatisfied mainly attributed their dissatisfaction to the late age of diagnosis and the long waiting lists in diagnostic centres. As a result, appropriate support and education were long in coming. They reported that this long delay resulted in loss of valuable time that could not be recaptured.

'Several years have passed away... we have lost our son as he used to be.' (13)

'Our son has lost one year in school because he attended a school in which he did not belong. When he finally started in an autism classroom, he said 'mummy, I am so happy !' (4)

Furthermore, parents attached great value to the disclosure of the diagnosis of ASD. The clearness of the information, the way in which the diagnosis was communicated, and the amount of information about the disorder, their individual

child, the impact on family life, and appropriate support and education were seen as essential.

'They used a lot of difficult words and the wording was long-winded.' (6)

'The professional said that our son was a little 'Rainman'. That was very clear for us. It was very stereotypical, but very clear. Now I wouldn't accept this way of talking about our child any more, but at that time, it was very clear.' (11)

'It was so good that they were honest with us, that they really communicated in plain terms. It was hard, but we really needed this clarity.' (2)

'I was very satisfied because the diagnosis was communicated in a very gentle way.' (5)

'We didn't receive information about the impact on family life. Nevertheless, this is very important, because such a child in your family... you can't imagine the implications for a family. It would be better if one could prepare oneself for this.' (10)

Finally, some parents found it indispensable that post-disclosure support was provided, since the amount and the content of the information given during the disclosure interview was so overwhelming.

'The paediatrician who conducted the disclosure interview assured us that we were ever allowed to take contact with her to ask questions. ... During the disclosure interview we were flooded with information. Because the disclosure of a diagnosis brings about a lot of emotions, we did not remember all that was said. Furthermore, a lot of questions arose a few days after the disclosure interview. Therefore, it is so important that you can call someone to answer those questions...' (2)

Access to appropriate education and support

During the interviews, parents whose children attended a special school often mentioned that they were not satisfied at all about finding an appropriate school or service for their child. Three main reasons accounted for this. Firstly, parents perceived the Flemish system for autism specific education and support as non-transparent. The search for appropriate support and education for their child with ASD often took a long time.

'I don't have the faintest notion of possibilities for education and support for our son. By coincidence, you hear something from other parents about appropriate services and schools.' (3)

'We didn't have any information about appropriate services and schools. There is nobody who informs you. When you're not informed, you miss out on appropriate help. There should be an umbrella organization where you can get help.' (7)

Secondly, parents complained about difficulties with referrals. They met up with wrong referrals, waiting lists, admission criteria, etc.

'The diagnostic instance gave us five addresses of suitable schools for our daughter. The first school we visited, told us that T. didn't belong there. That was a real shock for us.' (11)

Finally, parents were discontent with the supply of appropriate services and schools for children with ASD in Flanders. The services and schools that provide ASD-specific education and support were often dealing with long waiting lists. In particular, parents of children without intellectual disability were dissatisfied with the supply of appropriate support for their child. In addition, parents of older children were concerned about the continuity of support when their child would obtain the age of majority.

'The supply is limited. We are compelled to cover a long distance to school every day. And there is no suitable after-school child-care.' (11)

'There is not enough help. There are long waiting lists.' (12)

'There is almost no supply for children with ASD without intellectual disability. That's deplorable.' (1)

'Now she [daughter] consults an excellent child psychiatrist. Next month she will be 18 years old and as a consequence she has to find a new psychiatrist. That won't be easy for her. Continuity of support is essential for L.'s well-being.' (15)

The survey revealed that about a quarter of the children with ASD (24%) was registered on one or more waiting lists. In most of the cases (76%) it concerned a waiting list of an ASD-specific service or school, 9% of the children was waiting for multi-disability support or education, and 15% of the children was registered on both kinds of waiting lists. The average waiting time for autism-specific education or support was 9.65 months ($SD = 13.17$), for multi-disability education and support 12.98 months ($SD = 18.92$).

Education and support

More than half (55%) of all children who obtained the diagnosis of ASD before or during nursery school attended a general education school, 42% a special school and 4% received support from a special education teacher in a general education school. In primary school these were respectively 50%, 39% and 11% of the children and in secondary school respectively 67%, 21% and 12%.

Satisfaction with the degree to which the school fulfilled the needs of the child with ASD was measured on a 5-point Likert scale (1 = *very dissatisfied*; 5 = *very satisfied*). These satisfaction scores were compared between parents whose children received general education, special education, and general education with support. The results of the one-way ANOVA revealed a significant effect of group for satisfaction scores, both on the level of nursery and primary school (see Table 6).

Table 6
Satisfaction with degree to which school fulfils needs of the child, measured on a 5 point Likert scale

Level	General education <i>M (SD)</i>	Special education <i>M (SD)</i>	General education with support <i>M (SD)</i>	<i>df</i>	<i>F</i>	<i>p</i>
Nursery school	3.28 (1.16) ^a	3.95 (1.05) ^b	3.43 (1.13) ^{a,b}	2,158	6.845	.001
Primary school	3.12 (0.85) ^a	3.75 (1.06) ^b	3.50 (0.82) ^{a,b}	2,145	7.563	.001
Secondary school	3.43 (1.26)	4.00 (1.07)	3.25 (2.06)	2,37	0.689	<i>ns</i>

Note. Group means in the same row that do not share superscripts differ significantly at $p < .01$ using a post hoc-test (Scheffé). The superscript *b* indicates ‘significantly different’ from the *a* value. Two values with the same superscript indicate no significant difference.

A post-hoc test (Scheffé) was conducted in order to reveal which groups significantly differed. Significant differences were found between parents whose children attended a special school and parents of children in general education schools, both on the level of nursery and primary education. The group differences were in the direction of satisfaction being higher for the group of parents whose children attended a special school. These differences were not found for secondary education.

More than half of the parents (59%) mentioned that their child received autism-specific support from one or more service providers (e.g., home based treatment for children with ASD, rehabilitation, specialized boarding school). By means of a 5-point Likert scale (1 = *very dissatisfied*; 5 = *very satisfied*), parents indicated how satisfied they were with the autism-specific support their child received. The average score was 4.12 ($SD = 0.89$).

Only 11% of the children with ASD attended one or more multi-disability services (without an ASD-specific program; e.g., non-specialized home care, youth movement for children with a disability). The parents of children receiving these services gave an average score of 3.98 ($SD = 0.98$) on the 5-point Likert scale.

Finally, a third of the children (33%) went to one or more regular organizations (e.g., sports club, youth movement). The parents of children receiving these services gave an average score of 3.58 ($SD = 0.99$) on the 5-point satisfaction scale.

A paired samples t-test showed that parents were significantly more satisfied with the ASD-specific organizations in comparison with the regular organizations ($t(64) = -3.241, p = .002$). Differences between ASD-specific services and multi-disability services and between multi-disability services and regular organizations were not significant.

The interviews with the parents revealed that satisfaction with support and education considerably depended on different factors. These factors concerned both outline (e.g., communication means, parental involvement) and content (e.g., method, therapy) of received support. With respect to the outline factors, firstly, parents found it of the utmost importance to receive information about their child's daily functioning. Formal (e.g., parents' evening) as well as informal communication (e.g., short chat with the teacher) was highly esteemed by the parents, since their child with ASD often does not talk a lot about what happens in school. This information exchange was seen as a key factor in cooperating closely and in ensuring continuity for the child with ASD.

'We have a daily contact with the teacher either by an exercise book or by our son's diary. I am very pleased with that. The teacher writes down how D. is doing and in which activities he participated. That's very important. If there are problems in school, the teacher writes how she has dealt with it.' (12)

'It is very important that the teacher exchanges information with us, because F. doesn't tell anything.' (4)

Secondly, parents stressed that communication with the school or service has to be reciprocal. They appreciate it if professionals really listen to them and take parents' advice into account. The parents indicated that they find it very important to be involved and to think and work together with professionals when it concerns their own child.

'I think the extensive personal experience that we have with our child is very important. The teacher says that if we have a different opinion, we can always suggest alternatives for the benefit of our child's development. We act in close cooperation.' (9)

Thirdly, parents also mentioned the commitment and enthusiasm of the professionals as a key factor for satisfaction with the school or service. Many parents characterized the professionals as enthusiastic and highly motivated.

'... very involved, enthusiastic and motivated people. They are very interested and they even call when something happened at school or they show their interest in the exercise book. We don't feel like keeping a distance. Now we have a feeling of being accepted.' (11)

'The progression of our child completely depends on the teachers.' (5)

Finally, parents attached great importance to continuity of staffing. However, this was often not the case in schools and services. Whenever the staff changed, the children had to accommodate themselves to the new persons. This situation often resulted in adaptation problems.

'Currently, the school has to deal with a large turnover of staff. It always takes a long time for our son before he becomes acquainted with these new people.' (11)

On the level of the content of the support, parents perceived the following aspects as key factors for satisfaction. Firstly, most parents mentioned that it is fundamental that professionals really understand their child with his or her specific needs. Comprehensive knowledge of ASD was seen as an indispensable basis for understanding the child's unique needs.

'The teacher has a lot of knowledge about ASD and that is very important. That is one of the advantages of attending a specialized school: they know what our son needs and have the know-how to respond to his needs.' (12)

'Teachers in general education schools normally don't have the faintest notion of ASD and of ways to support children with ASD adequately. That's a very serious shortcoming. When they are not informed, they can't know how to support a child with ASD in their class. Thanks to the excellent communication between the teacher and us, and thanks to the interest and goodwill of the teacher to attend ASD-specific training, M. [son] is really doing fine at his school.' (1)

Secondly, although almost all parents indicated that they found it very important that activities and adaptations are individualized, only a minority of the children had an Individual Educational Plan (IEP). Some parents found this regrettable because they perceived it as a communication tool, but most parents assumed that an IEP was not really necessary since the staff clearly set goals for each individual child and parents got involved in these discussions. Others were even not informed about the fact that the school or service worked with an IEP.

'There is no written IEP. It is not necessary because the teachers don't just act inconsiderately.' (5)

'Despite the fact that they promised that there would be an IEP, there isn't. We really regret that, because it's a tool to cooperate.' (6)

ASD-specific knowledge and training

Less than half of the parents (38%) found that they were well or very well informed about ASD. Parents received mainly information from the Flemish parent organization (68%), a training centre for autism (31%), the special school of their child (16%), and/or the service provider (13%). Eleven percent of the parents were not at all informed about ASD. We asked the parents to rate their ASD-specific knowledge on a 5-point Likert scale (1 = *very little*, 5 = *very much*). Parents who were regularly informed about ASD estimated their knowledge of different aspects of ASD to be higher than parents who received little or no information about ASD (see Table 7).

Table 7
Knowledge of different aspects of ASD in parents who are regularly informed and parents who were little or not informed, measured on a 5 point Likert scale

Knowledge of ...	Regularly informed <i>M (SD)</i>	Little or not informed <i>M (SD)</i>	<i>df</i>	<i>F</i>	<i>p</i>
Etiology and prevalence	3.39 (.94)	2.60 (1.10)	1,230	30.586	.000
Features	4.13 (.69)	3.42 (.97)	1,230	34.959	.000
Course	3.49 (.91)	2.54 (.91)	1,229	59.426	.000
How to support your child	3.55 (.92)	2.55 (.92)	1,228	53.914	.000
Available service provisions	3.34 (.87)	2.31 (.87)	1,227	75.677	.000

Concerns and future needs

Concerns about the future were measured on a 5-point Likert scale (1 = *not at all concerned*, 5 = *very concerned*). As Table 8 indicates, parents of children with ASD were concerned about the future. The greatest concerns were related to issues about the disorder of their child: ‘My child’s social development’, ‘Acceptance of my child by others’ and ‘Development of friendships by my child’.

Furthermore, 63% of the parents estimated the probability that their child would receive desired support in the future lower than 40%. Almost half of the parents (49%) would like to appeal more to friends and family in the future to care for their child with ASD. Other needs that parents reported were: more adjusted services for persons with autism (73%), more financial support (46%), and more training about autism (44%).

Table 8
Concerns about the future, measured on a 5 point Likert scale

Concerns about...	<i>M</i>	<i>SD</i>
The quality of my child's education	3.54	1.10
My child's progress in school	3.70	1.04
Medical support for my child	2.92	1.17
Support in social activities of my child	3.87	0.97
My child's social development	4.24	0.88
My child's safety	3.86	0.95
My child's health	3.02	1.17
Acceptance of my child by others	4.21	0.88
Development of friendships by my child	4.24	0.86
My child's sexual development	3.73	1.03
My child's puberty	4.08	0.83
Financial security of my child as an adult	3.99	1.01
Set up house	3.91	1.01
Love and marriage as an adult	4.03	0.95
Finding a job as an adult	3.89	0.93
My child as an elderly person	3.75	1.18

All parents were asked to rate the quality of the received support and education of their child on a 10-point scale. A score of 10 indicated the ideal support in ideal circumstances for their son or daughter. The average score parents gave was 5.82 ($SD = 2.14$). A forward regression analysis was performed to determine the variables making the largest contribution in predicting the criterion variable 'overall satisfaction with support and education for the child'. Based on previous research about the evaluation of services for persons with ASD (as described in the introduction), the following independent variables were considered for predicting the overall satisfaction of the parents: 1) time between first consultation and final diagnosis, 2) knowledge of available service provisions, 3) knowledge of features of ASD, 4) parental involvement in the school or service, and 5) waiting for appropriate support or education.

The best single predictor was parental involvement. Prediction then was significantly improved by the addition of the variable ‘knowledge of available service provisions’, and then by the addition of ‘time between first consultation and final diagnosis’ (Table 9). Adding ‘knowledge of features of ASD’ and ‘waiting for appropriate support or education’ did not significantly improve the prediction.

Table 9
Results of a forward regression analysis predicting overall satisfaction

Predictors	<i>R</i>	<i>R</i> ²	<i>F</i> Change	<i>p</i>
PI	.444	.197	47.548	.000
PI, Knowledge SP	.508	.258	15.854	.000
PI, Knowledge SP, Time	.563	.317	17.535	.000

Note. PI, parental involvement (measured on a 5-point Likert scale); Knowledge SP, knowledge of available service provisions (measured on a 5-point Likert scale); Time, time between first consultation and final diagnosis

DISCUSSION

Literature about formal support from professionals and services suggests that families often lack appropriate support for their child with a disability (Florian & Krulik, 1991; Sloper & Turner, 1992). Considering the fact that support can act as a buffer against the demands of caring for a child with a disability on the one hand and that parents themselves consider professional help to be very important in rearing their impaired child on the other hand, it is essential that predictors of satisfaction and the experiences of parents with formal support are examined. These findings can function as a driving force for policy makers, professionals, and other stakeholders to optimize professional intervention for persons with a disability. In this study we examined the experience and satisfaction of Flemish parents of children with ASD regarding diagnosis, education, and support for their child. The data both support previous literature about experiences of parents of children with ASD and provide additional insights.

We found that parents were not univocally positive about the education and support their child with ASD received in the past. Firstly, with respect to early identification, our study revealed several problems confirming existing literature about the diagnosis of ASD. Although there is a substantial increase in research knowledge about early identification of autism, the age of diagnosis in primary school children in Flanders is still almost 6 years. A similar result was found in the UK (Howlin & Moore, 1997) and the USA (Mandell et al., 2002). The results of our study revealed that parental satisfaction with the diagnostic process was significantly associated with the age of diagnosis. The delay of more than 2 years between parents' first professional consultation concerning their child and the final diagnosis is unacceptably long. Since autism can be reliably diagnosed in children as young as 2 years (Lord, 1995; Moore & Goodson, 2003) and early intervention results in better outcome for persons with ASD (Corsello, 2005; Gresham & MacMillan, 1998; Howlin, 1997; McEachin, Smith, & Lovaas, 1993), it is very important that professionals -if necessary- refer parents with early concerns much more appropriately and speedily. Professionals who are often first consulted by the parents, such as school psychologists, general practitioners, and paediatricians should be more informed about general features of developmental disorders and appropriate services experienced in identifying developmental and behavioural problems.

The delays and problems in obtaining a formal diagnosis for the child with ASD are often only the first confrontation with difficulties many parents experience in obtaining appropriate support, education, and information for their child. A third of the parents mentioned that they did not receive information about ASD during the disclosure interview and about half of the parents was not informed about how ASD manifests itself in their own child. Even less parents got advice about how to support their child and about which services and schools are suitable for children with ASD. Consequently, for many parents the disclosure interview yields more questions than answers about their child. Our results revealed that parental satisfaction with the diagnostic process was significantly associated with the amount of information parents received during the disclosure interview. A study of Brogan and Knussen (2003) underlined the enormous importance of the content and the quality of the information given at the time of the disclosure interview. All parents should receive enough information about

ASD, about how to support and understand the individual child, and about appropriate services and schools for their child, so that the disclosure interview is a solid base for the family to understand how to meet the child's unique needs.

Besides difficulties with the diagnosis, a second source of dissatisfaction of the parents was the accessibility of appropriate support and education for their child with ASD. The non-transparency of the Flemish school and support system for persons with a disability, the long waiting lists, and the limited supply of specialist schools and services for persons with ASD are the major causes of discontentment. Mainly parents of children with ASD without intellectual disability experience many difficulties in finding ASD-specific support for their child.

Despite the accessibility problems, parents are generally satisfied with the quality of the education and support their child receives. Nevertheless, satisfaction scores were significantly higher for the special schools and services than for the general ones. Key factors for satisfaction with the quality of the received education and support were: mutual information exchange about the child with ASD, the child having an individualized programme, knowledge and expertise of the professionals, and continuity of staffing. Since parents were less satisfied with general education schools and regular services, it is crucially important that more attention is paid to training and support for regular facilities supporting persons with ASD. Congruently, parents were significantly more satisfied with regular education when their child was supported by a special education teacher in the general education school. The ignorance of ASD in many regular facilities impedes professionals from understanding and taking into consideration the special needs of the child with ASD. Minor changes (such as training and external support from experts) could turn a regular school or service into a more adapted and thus a less restrictive environment for the child with ASD.

Not only professionals should easily access information and training about ASD, it is just as important that parents are well-informed about features of ASD in general and their own child in particular. However, the results of our study revealed that only 38% of the parents found that they received much or very much information about ASD. This is consistent with results of previous research of

Nesbitt (2000) and Whitaker (2002), in which the accessibility and quality of information about ASD are discussed. Our results demonstrated that being regularly informed is associated with a better knowledge of different aspects of ASD. Since training and information are associated with a clear understanding of the disorder, more effort should be made to inform all parties concerned regularly.

Overall, we found that general parental satisfaction with received support and education is predicted by 1) parental involvement in formal support, 2) knowledge of available service provisions, and 3) time between first consultation and final diagnosis. Not only these predictors of parental satisfaction are important to pay attention to, the results of the qualitative analyses of the interviews revealed many other important weaknesses and strengths regarding current diagnosis, education, and support for persons with ASD. Since Brogan and Knussen (2003) and Peeters (2000) emphasized that the quality of life of an individual with ASD may largely depend on the way we adapt the environment to his or her needs, the importance of a continuing investment in the optimization of education and support for persons with ASD (in both special and general education and support settings) cannot be overestimated.

There are several limitations that should be acknowledged when interpreting the results of this study. First, it is unclear whether the parents who responded to the survey are representative of the larger population of families that have a child with ASD in Flanders. Although the participants in our study were from different social classes, lived in different geographical areas in Flanders, and their children with ASD varied in ages, diagnostic label, support experiences, etc., a selection bias may have affected the results of our study.

Secondly, given the geographical delineation of our study to the Flemish part of Belgium, this study should be understood as a case study of parental satisfaction with education and support for children with ASD in Flanders. Consequently, the external validity of the study is confined to the population of parents with children with ASD in Flanders.

Finally, since we had limited information about the actual support needs of each individual child whose parents completed the questionnaire, we were not able

to determine the relevance of the child's characteristics for parents' experiences and satisfaction with received education and support. However, the results from the interviews enabled us to make some preliminary statements about the importance of some child characteristics for parental satisfaction with education and support.

Firstly, parents of children without intellectual disabilities generally experienced more difficulties with finding appropriate support for their child. Given the cognitive capabilities of those children, a general education school is often much more appropriate than special education. However, since general education schools are commonly not familiar with ASD, additional support is often required.

Secondly, parents of older children were often concerned about the continuity of the support when their child attains the age of majority. Because many services in Flanders support either minors or adults, continuity of support can often not be guaranteed at the age of 18.

Finally, the interviews revealed that, regardless of the age, intellectual disability, and support needs of the child with ASD, parents attach equal importance to issues identified as being characteristic for support of high quality, such as individualization, a close cooperation with professionals, continuity of staffing, commitment and enthusiasm of professionals, and ASD-specific knowledge.

CHAPTER 4

SUPPORT NEEDS AND EXPERIENCES IN ADULTS WITH AUTISM SPECTRUM DISORDER: A QUALITATIVE ANALYSIS¹

ABSTRACT

This study explored the perspectives of high functioning adults with autism spectrum disorder (ASD) regarding met and unmet support needs. Fifty-eight high functioning adults diagnosed with ASD were interviewed using the Camberwell Assessment of Need (CAN). Transcripts of the interviews were analyzed for emergent themes. Support needs were generally met for the areas requiring practical support, such as living arrangement, food, etc. The domains concerning interpersonal relations and psychosocial well-being demonstrated the highest proportion of unmet to total needs. In addition, several themes emerged from the interviews, including difficulties with obtaining a formal diagnosis, participants' needs for individualized, comprehensive, and flexible support, and the importance of self-determined choices.

¹ Renty, J., & Roeyers, H. (2005). Support needs and experiences in adults with autism spectrum disorder: A qualitative analysis. *Manuscript submitted for publication.*

INTRODUCTION

Although the unique support needs of children with autism spectrum disorder (ASD) have extensively been examined in the past (Bromley, Hare, Davison, & Emerson, 2004; Gabriels, Hill, Pierce, Rogers, & Wehner, 2001; Renty & Roeyers, in press, see Chapter 3; Sperry, Whaley, Shaw, & Brame, 1999), until now, no efforts have been undertaken to systematically describe and analyze the support needs and experiences of adults with ASD. Nevertheless, outcome research in adulthood revealed that few high functioning individuals with ASD were considered to be fully self-supporting. Howlin, Goode, Hutton, and Rutter (2004) reported in a recent study that a large proportion of adults with ASD (57%) had a 'poor' or a 'very poor' outcome. Despite their cognitive abilities, attainments in many areas were disappointingly low: less than a quarter of the adults had obtained formal qualifications at school, only a third was engaged in some form of employment (which was in more than half of the cases sheltered, supported, or voluntary), more than three quarters lived with their parents or in a residential setting, and only around a quarter was described by the parents as having friends. Other outcome studies of high functioning adults with ASD have described similar findings (for an overview: see Howlin (2000) and Tsatsanis (2003)). Lord and Venter (1992) and Mawhood and Howlin (1999) stated that the ability of high functioning persons with ASD to function adequately in adulthood may depend on the degree of support offered. Correspondingly, the quality of life of high functioning adults with ASD is significantly predicted by support characteristics (Renty & Roeyers, 2005b, see Chapter 5). Mainly unmet support needs were highly associated with lower levels of quality of life, particularly for needs concerning interpersonal relationships, daily activities, and information on the disorder and on intervention. Consequently, a thorough assessment of support needs is essential when designing and providing appropriate support.

The concept of 'need' is an ambiguous term. Needs can be defined as 'an objective lack of health or well-being' or as 'a lack of access to appropriate forms of care or adequate interventions' (Brewin, 1992). The Camberwell Assessment of Need (CAN), which was chosen for the purpose of this study, embodies the latter approach and consequently provides a subjective assessment of support needs

according to the view of the individuals themselves. The information about unmet support needs and about both favourable and negative support experiences of adults with ASD has the potential to assist the informal network, professional supporters, and policy makers with the development of meaningful and effective interventions, matched to the individual's needs and concerns.

Previous studies using the CAN among samples of individuals with psychiatric disorders (Freeman, Malone, & Hunt, 2004) revealed that unmet support needs mainly consisted of needs in the areas of information about condition and treatment, company, psychological distress, intimate relationships, sexual expression, daytime activities, physical health, and transport. Humberstone (2002) concluded that, while a high level of support seems to ensure that the basic needs of individuals with psychiatric disorders have been met adequately (housing, food, and medication), support networks frequently overlooked social and psychological needs as well as daytime activities. Besides, Freeman and colleagues (Freeman et al., 2004) found that many persons with psychiatric disorders felt that formal services would not be able to address their support needs for intimate relationships or sexual expression.

Despite the relatively high amount of studies on support needs in adults with psychiatric disorders, there is only one study in which the CAN was used for high functioning adults with ASD (Engström, Ekström, & Emilsson, 2003). This study reported on the psychosocial functioning of 16 individuals with Asperger's Disorder or high functioning autism. The authors found that their sample generally had extensive support needs: only one person had a regular job, one person lived with minimal extra support, all persons were unmarried and five had a intimate relationship. Specific met and unmet support needs as well as particular support experiences were not discussed in the paper. However, the identification of unmet support needs in adults with ASD opens the way for better-targeted support provision that fully meets the needs of these adults. Therefore, detailed information on support experiences provides the best starting-point to improve specific areas of support.

The purpose of the current study was fourfold. Firstly, we intended to identify support needs of high functioning adults with ASD. Secondly, the type and

frequency of met and unmet support needs in adults with ASD were explored. Thirdly, the amount of received informal support and the amount of received and needed formal support were described. Finally, the specific support experiences reported by adults with ASD were analyzed in depth.

METHOD

Participants

Participants in the present study were recruited as part of a larger study assessing quality of life and support characteristics in adults with ASD (Renty & Roeyers, 2005b). The sample of adults with ASD was drawn from two sources. Firstly, participants were recruited through advertisements in an ASD advocacy group newsletter and a newsletter of the Flemish user organization for ASD. Secondly, persons who participated in previous autism research at our laboratory were invited to take part in the present study. The participants were 58 adults with ASD, living in Flanders (Belgium). The adults in the study had to meet two criteria: 1) all participants were in the normal range of intelligence, demonstrating a full scale IQ of 70 or more (assessed by the WAIS-III; Wechsler, 2000); and 2) the participants had all been diagnosed by a multidisciplinary team of experienced clinicians and fulfilled established DSM IV-TR criteria for autism, Asperger's Disorder or Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). Three additional adults were tested but not included in the final sample due to IQ-scores under 70.

Participants ranged in age from 18 to 57 years, with an average age of 28.34 ($SD = 9.78$) years. Seventy-four per cent was male. Thirty-six per cent of the adults was diagnosed with ASD, 34% had a diagnosis of Asperger's Disorder, 21% of autism and 9% of PDD-NOS.

Measure

Age, gender, diagnostic information, marital status, education, living arrangements, and working circumstances were documented. Needs were assessed using the Camberwell Assessment of Need (EU-version; McCrone et al., 2000; Phelan et al., 1995). The CAN is a semi-structured interview comprising the subjective perception of support needs in 22 domains. The areas of need which are covered in the CAN are: Accommodation, Food, Housekeeping, Self-care, Daytime Activities, Physical Health, Psychotic Symptoms, Information about Condition and Treatment (here: Information on ASD and ASD-specific Intervention), Psychological Distress, Safety to Self, Safety to Others, Alcohol, Drugs, Company, Intimate Relationships, Sexual Expression, Child Care, Basic Education (here: Household Administration), Telephone Use, Transport, Money, and Social Benefits. Although the CAN was initially designed to describe the needs of persons with psychiatric disorders, its use for persons with ASD has been introduced by Engström and colleagues (2003).

The CAN follows an identical rating procedure for all 22 need domains and each domain is evaluated in four sections. In the first section the interviewer rates whether a need exists, and if it does, whether it concerns a met or an unmet need (0 = *no need*, 1 = *no/moderate problem because of continuing intervention*, 2 = *currently serious problem irrespective of any ongoing intervention*). A rating of 1 is defined as a met need and a rating of 2 is defined as an unmet need. If a need is recorded as being present (score 1 or 2), the second till the fourth section are applied. In the second section further information is asked to gain insight in current level of informal support (i.e. help from friends or relatives) (0 = *none*, 1 = *low*, 2 = *moderate*, 3 = *high*). The third section uses the same rating as the second one and focuses on the amount of support actually received from professional services and the amount of support needed from professionals. Finally, in the fourth section satisfaction with both the adequacy and the amount of support received are rated (0 = *no*, 1 = *yes*). Summary need scores are calculated by aggregating the number of met and unmet needs over the 22 items. Summary informal and formal support scores are calculated by adding the support scores in respectively the second and third section over all 22 domains.

Several studies demonstrated that the CAN is a valid and reliable instrument for assessing the needs of people with severe mental illness (Falgaard-Nielsen et al., 1999; Hansson, Bjorkman, & Svensson, 1995; McCrone et al., 2000; Phelan et al., 1995). In the present sample all interviews were rated by three independent raters. The intraclass correlation coefficients were high for all section scores of the CAN (.92 - .97), which reflected that the inter-rater reliability was very good. In case of different ratings, the three raters discussed the situation in order to reach a consensus score.

Data analysis

Descriptive and reliability statistics of the CAN-scores of all 58 participants were computed using SPSS, Version 12.0. To further explore the subtle, subjective, and complex aspects of support needs and experiences in adults with ASD, a qualitative data analysis approach was chosen. By means of interviews, we were able to focus on specific domains of need without restricting the potential for exploration. With permission of the participants, all in-depth interviews were audio-recorded and transcribed verbatim. The interviews were imported into MAXqda (VERBI Software, 2001; Berlin, Germany). This software was designed for qualitative data analysis and assists with storage, coding, retrieval, and analysis of text segments. The method of data analysis adopted was the 'Framework method', devised by Ritchie and Spencer (1994). Essentially, this method involves five key stages: familiarization, identifying a thematic framework, indexing, charting, and finally, mapping and interpretation. The familiarization phase involved an immersion in the data by listening to the tapes and re-reading the transcripts. For the development of a thematic framework, different new themes (based upon issues the participants raised themselves) were identified in addition to the a priori themes that were set considering the semi-structured nature of the interview. During the indexing phase the thematic framework was systematically applied to the interview transcripts until saturation was reached and consequently no new themes emerged from the data. Therefore, even though the transcripts of all 58 interviews were available in this study, the researchers continued to index the interview transcripts up to the point where analyses indicated that saturation had been achieved. Eventually, 26 interview transcripts were analyzed in depth. During

the forth phase of the data analysis (i.e. the charting phase), the data were lifted from their original context and rearranged according to theme. In the final phase, the indexed and charted data were re-examined to seek for patterns and explanations within the data.

In the results section of this paper, illustrative quotations are provided, followed by a participant number. These quotations, selected for their relevance to the themes, enable the reader to judge the interpretations of the authors.

RESULTS

Support needs

The CAN interviews provided a clear picture of the subjective support needs of the adults diagnosed with ASD. In this section, the most prevalent support needs will be discussed: living arrangement, psychological distress, daytime activities, ASD-specific information, and interpersonal relationships.

Firstly, a significant proportion of adults with ASD reported a support need in the areas Housekeeping (85%), Food (78%), Accommodation (76%), Social Benefits (76%), and Household Administration (55%). These areas are more or less associated with one's living arrangement. Just over half of the adults ($n = 32$) lived with their parents, 11 individuals lived with support of professionals, 6 lived independently, 5 lived together with a partner, and 4 people lived in a residential institution. Although more than half of the adults still lived with their parents, some had the prospect of moving to an independent living arrangement. These adults consequently did not report a support need with respect to accommodation. Other adults felt unsure about living independently, on the one hand because they were afraid of feeling lonely, on the other hand because they perceived their current living arrangement with their parents as very comfortable in terms of housekeeping, cooking, etc.

'I still live with my parents and I am satisfied with that. It is a comfortable situation because I work from dusk till dawn. ... My father submitted an application for supported living for me, but I am not bursting to live alone.' (5)

'I would not like to live on my own. I would be too lonely.' (3)

Secondly, approximately two thirds of the adults (66%) reported a support need with respect to Psychological Distress. Psychological problems frequently mentioned by the adults were high trait anxiety, depression, panic disorder, poor self-esteem, and suicidal thoughts. Although none of the individuals mentioned a diagnosis of any specific psychiatric co-morbidity, 33% was on psychiatric medication that was primarily prescribed to reduce depression, anxiety, and agitation.

Thirdly, the participants were asked about their employment status and their current occupation or daily activities. More than half of the adults (57%) reported a support need in this area of the CAN. Seventeen adults were enrolled in training programs, 16 persons had a competitive job, 8 were in supported employment, 3 were in sheltered employment, and another 3 had a day activity programme (these categories are not mutually exclusive because some participants were part time in several day activities). Thirteen individuals were unemployed and 1 person was retired. Although problems with daytime activities were fairly common in high functioning adults with ASD, some adults did not want to be supported with respect to their daily activities and consequently reported no support need, despite the problems they experienced.

'Every day I stay in bed until noon. In the afternoon I take the train to A. [city] I even have a season ticket to go to A. When I arrive, I buy a German newspaper, I drink one coffee, I walk around for a while and then I go back home. Every day I go through the same programme. I never get tired of it, so I don't need to be supported.' (40)

The greater part of the adults had some negative experiences in terms of daytime activities. The difficulties they faced originated from various factors: some people had not been able to obtain or hold the job that fitted their capabilities and

qualifications because of social aspects, communication aspects, or sensory overload; some found no meaningful activities during leisure time and as a consequence mentioned they frequently felt bored; other adults had enough work but mainly experienced difficulties with organization and planning.

'I frequently experience problems with the transition from one activity to another. It's very difficult for me to start up something new... I really have to think about it and I must take time to make the transition. Sometimes, I even must draw up a step-by-step plan and then I function reasonably.' (36)

'I have had about 20 jobs, which all came to a bad end. I always had a problem with being commanded. For example, when I was working on one thing, then I just couldn't accept the order to change my planning because something more urgent had to be done first. I first finished the job I was working on and then I carried out what I was ordered to do instantly.' (37)

'I am a qualified nurse, but currently I work in a rest home as attendant. It was our company doctor who decided that I had to move over to the job in the rest home.' (33)

Fourthly, more than half of the participants (52%) reported a support need with respect to ASD-specific information. The qualitative analysis of this section of the CAN revealed that most adults were satisfied with the information they received about the general characteristics of the disorder, but many adults indicated the need for more personal information, thoroughly tailored to their individual needs. Mainly information about the individual manifestation of ASD and information about how to cope with difficulties resulting from the disorder was needed.

'I don't really have a need to get more information about the disorder in general, but rather about how to cope with ASD. There is much literature about the symptoms and the features, but I can't find anything about how to become able to give it a place in my life, without falling by the wayside.' (10)

'I would like to get more information about how ASD is manifest in myself. When I read books about ASD, they sometimes write seemingly inconsistent things. A book provides very broad information about ASD and when you adopt everything into your personal situation you become disorientated. Therefore I need a professional who explains clearly and thoroughly how to cope with my ASD.' (53)

Finally, although the participants commonly reported difficulties with starting and maintaining friendships and intimate relationships, less than half of them (respectively 43% and 29%) reported a support need in the CAN areas Company and Intimate Relationships. The majority of the participants ($n = 39$) had no intimate relationship, 16 persons had a partner and 5 of them lived together or were married. Three individuals were divorced. Some adults did not want to be supported because they were resigned to the fact that they have few friends or no partner, others felt that there is no professional support available in these areas that applies to their personal needs. These latter adults held the opinion that friendships and interpersonal relations are rather a private thing. Consequently, they were reserved towards support from the formal or informal support network in these areas.

'My mother recommended a book about making friends. I haven't read it. I don't know why I haven't ... I think I have now accepted that I have almost no friends. Those books are very theoretical and I have really mastered the theory about making friends, but I can't put it into practice ... Actually, I have accepted that I'm unsocial. It has become my style of living.' (45)

'I don't have much friends, but I think that they [professional support network] can't do much about it. Making friends is something that you have to do on your own.' (15)

Type and frequency of met and unmet support needs

Table 1 shows the (met and unmet) support needs profile of the participants, together with the unmet/total needs ratio.

Table 1
Number of adults with ASD presenting needs in the 22 need areas of the CAN (CAN section 1) (n = 58)

CAN domain	Severity rating			Ratio unmet / total need (%)
	0 No need <i>n</i> (%)	1 Met need <i>n</i> (%)	2 Unmet need <i>n</i> (%)	
Housekeeping	9 (16)	45 (78)	4 (7)	8
Food	13 (22)	42 (72)	3 (5)	7
Accommodation	14 (24)	40 (69)	4 (7)	13
Social benefits	14 (24)	34 (59)	10 (20)	23
Psychological distress	20 (35)	25 (43)	13 (22)	34
Daytime activities	25 (43)	26 (45)	7 (12)	21
Household administration	26 (45)	32 (55)	0 (0)	0
Information on ASD and ASD-specific intervention	28 (48)	18 (31)	12 (21)	40
Company	33 (57)	11 (19)	14 (24)	56
Money	35 (60)	22 (38)	1 (2)	4
Transport	36 (62)	20 (35)	2 (3)	9
Telephone	40 (69)	14 (24)	4 (7)	22
Intimate relationships	41 (71)	8 (14)	9 (16)	53
Self-care	43 (74)	15 (26)	0 (0)	0
Sexual expression	49 (85)	5 (9)	4 (7)	44
Physical health	49 (85)	7 (12)	2 (3)	22
Safety to self	53 (91)	3 (5)	2 (3)	40
Psychotic symptoms	53 (91)	5 (9)	0 (0)	0
Child care	55 (95)	2 (3)	1 (2)	33
Safety to others	55 (95)	3 (5)	0 (0)	0
Alcohol	58 (100)			
Drugs	58 (100)			

Met needs generally were most prevalent in the areas of practical support (Housekeeping, Food, Accommodation, and Social Benefits). Unmet needs were particularly prevalent in the areas Company, Psychological Distress, and Information on ASD and ASD-specific Intervention. The prevalence of a met need can be viewed as an indicator of the amount and type of support provided by the informal and formal support network. However, how well these networks are tuned to the individual's needs profile is better represented by the ratio between unmet and total number of needs (i.e. sum of met and unmet needs) (Middelboe et al., 2001). Consequently, need areas of possible neglect or lack of successful intervention are identified by a high fraction of unmet needs. This was the case for need areas concerning interpersonal relations (Company, Intimate Relationships, Sexual Expression, and Child Care) and psychosocial well-being (Psychological Distress, Information on ASD and ASD-specific Intervention, and Safety to Self).

Amount of formal and informal support

The amount of support received from informal and formal resources is displayed in Table 2, along with the amount of support needed from formal resources within each area.

In general the percentages of adults appealing to support are much higher for the informal support network than for professional support (except for 3 areas: Psychological Distress, Psychotic Symptoms, and Daytime Activities). The percentages of adults with ASD receiving 'moderate' or 'high' levels of informal support were highest for the areas Food (91%), Accommodation (92%), and Housekeeping (72%). The same line of reasoning was followed for both received and needed formal support, with the proportion of received support being highest for the areas Psychological Distress (63%), Psychotic Symptoms (60%), and Daytime Activities (33%) and the proportion of needed formal support being highest for Psychological Distress (76%), Company (72%), and Information on ASD and ASD-specific Intervention (70%). It is important to notice that all percentages are based on the number of adults reporting a need in the concerning area of the CAN.

Table 2
Subjective ratings of received informal support, received formal support and need for formal support (CAN section 2 and 3)¹

CAN domain	Informal support ²	Formal support ²	Need for formal support ²
Food	91	20	24
Accommodation	82	25	36
Housekeeping	72	18	22
Transport	64	9	18
Social benefits	55	41	51
Psychological distress	50	63	76
Household administration	47	9	13
Information on ASD and ASD-specific intervention	43	37	70
Telephone	39	6	11
Child care	33	0	33
Safety to others	33	0	0
Intimate relationships	29	18	29
Daytime activities	24	33	42
Sexual expression	22	11	33
Physical health	22	0	11
Psychotic symptoms	20	60	60
Self-care	20	7	7
Money	17	29	29
Company	12	32	72
Safety to self	0	0	20

¹ All figures are based on the number of adults with ASD reporting a need in the CAN area of question (i.e. a rating of 1 or 2 in the first section of the CAN)

² Figures indicate percentages of adults with ASD reporting 'moderate' or 'high' levels of support (i.e. a score of 2 or 3 in the second and third section of the CAN)

Support experiences reported by adults with ASD

Diagnosis

The reported age of diagnosis ranged from 2 years to 54 years. Eleven participants had received the diagnosis during childhood (0-12 years), 20 persons were diagnosed as adolescent (12-18 years), 18 individuals were between age 18 and 30 and 9 were not informed about the diagnosis before the age of 30. Many adults reported on the problems they experienced with obtaining a formal diagnosis of ASD. This process often was long in time and full of difficulties. Most participants saw various combinations of professionals before a formal diagnosis was obtained. They were discontent about the length of delay between first professional consultation and final diagnosis. Some adults were indignant about the fact that, after years of struggling, the diagnosis was finally made as a result of atypical symptoms indirectly resulting from ASD.

'We consulted our general practitioner because I was pestered in school, which in turn resulted in bad school results. I ended up in a severe depression and lost a lot of weight. It is because of that weight loss that we consulted our GP. He advised us to consult a psychiatrist, who finally made the diagnosis of ASD. It was really by coincidence that I obtained the diagnosis.' (4)

'When I was six or seven years old, my parents consulted a psychiatrist because of my problematic behaviour. I behaved in a way they didn't understand. Thereafter we consulted many other psychiatrists, but no one made a diagnosis of ASD. When I was eleven years old I was admitted into a psychiatric hospital for children, where I stayed for one and a half year. Finally, at age nineteen we consulted another psychiatrist who made the diagnosis of autism.' (10)

Other adults were incensed by the fact that, after years of professional consultation, it was not a professional, but they or their parents themselves who first got the idea that the problems were caused by a disorder within the autism spectrum.

'From early childhood on, my parents noticed that I was not like the other children. They have been consulting specialists for years. Those consultations ended up without any diagnosis or with a wrong diagnosis, for example with H. [psychiatrist] I was diagnosed with ADHD. Finally, a television program about autism, in which I recognized myself, got the ball rolling. I let it sink in for several months, thereafter I told it to my parents. They got in touch with a rehabilitation specialist who referred us to a specialized diagnostic team for autism, at which I finally obtained the diagnosis of Asperger's Disorder.' (27)

'It so happened that I read an article about autism in a magazine and I identified with the person in that article. Afterwards I looked on the internet and I recognized more and more. From that time on I was convinced of having ASD and I made an appointment with a psychologist who finally set the diagnosis.' (16)

Not only the difficulties regarding obtaining a formal diagnosis of ASD, but also the importance of the way in which the disclosure process happened, is commented in many interviews. The participants stress the importance of the adequacy and clarity of the information received, the amount of emotional support provided, the amount of information about access to financial benefits and support services, and post-disclosure support. In some cases the way the disclosure happened had a strong impact on the person's life.

'The disclosing doctor informed us extensively, but he was very straightforward and crude. He told my parents that I would never be able to live independently, to have a regular job, etc. I have rejected the diagnosis for a long time because I wanted to prove that I am able to care for myself. I wanted to show that everything he had said was false.' (21)

'The psychiatrist tried as hard as she could to explain the diagnosis clearly, but it was somewhat impersonal. She told it in a general way, not very individual.' (4)

'My psychiatrist gave us a lot of information and explained the diagnosis in great detail, but I needed quite a long time to deal with the diagnosis

and to accept it. I went through different stages of acceptance and once I accepted the diagnosis fully, I 'became' it for a certain time. At that moment, it was the only thing that mattered in my life, everything revolved around that diagnosis. But one year ago, I thought: 'I have ASD, but that doesn't mean that it has to dominate my life'. It took me a very long time to come to that point.' (10)

'The psychiatrist disclosed the diagnosis, but he did not refer me to a specialist support service or a professional who is familiar with supporting persons with ASD. I was not assertive enough to ask the psychiatrist for this information. I got no practical support at all, I had to sort it out all alone. It took about one and a half year before I was on the right track.' (11)

Preferred type of support: general features

The adults hold strong views about features of effective and substantial support. The importance of being supported towards autonomy, self-realization and self-determined choices is mentioned by many adults with ASD. Nevertheless, this was not always the case for the participants in our study.

'At home, my mother does quite a lot for me. For example, she buys my clothes, she lays my clothes out, etc. It is sometimes comfortable, but most of the time I would like to do it myself.' (17)

'Everyone who takes part in this study may say: 'there are not enough support facilities for people with autism', but I hold the opinion that I don't want to depend on other people for the rest of my life. I want to learn how to cope with the problems resulting from my disability, because I know ASD is incurable. I would be very disappointed if I couldn't live an autonomous life. I would like to learn how to cope with difficulties arising from ASD.' (25)

'I live independently with support from a professional service. This [support] mainly consists of help with household administration,

housekeeping and – if necessary – emotional support. It is an excellent kind of support because I can live on my own but still have someone to rely on. That makes it possible to become more and more independent.’ (9)

Furthermore, adults with ASD explicitly mentioned their need for support by a kind of personal assistant or coach. This person should only be available when needed and thus not all the time. Ideally, this kind of support would be comprehensive, personal, and characterized by respect, equality, flexibility, and partnership.

‘I only have one personal coach who supports me very well and I really made headway with his help. He supports me in a very personal way, he has made an individual support plan with points of particular interest which I have to work on. It is much more intensive and personal than I have ever known. He keeps a close track of my personal development, without being patronizing.’ (27)

‘I feel very comfortable with the consultations with S. [psychiatrist]. He treats me as an equal, not as someone with Asperger’s Disorder who should be helped. Therefore I really accept his advice.’ (14)

‘I sometimes have a question that I would like to address to someone who is familiar with ASD. I know that I could get help from D. [expert/trainer], but I am always afraid to bother her. I always have the feeling that I disturb her at her work and I don’t even know if I’m allowed ask her questions. I would like to know someone [professional] who I can get in touch with when I need it.’ (11)

The need for support that is based on a thorough knowledge and understanding of ASD is also mentioned. Adults with ASD found it crucial to have access to autism-specific support.

‘I frequently contacted B. who is a mother of 2 children with autism. ... It is very difficult to find someone who is familiar with ASD in adults with normal intelligence. For children it is much easier to find professionals who are acquainted with ASD, but for us ...’ (19)

'Since June I have a personal assistant who is expert in ASD. When she came the first time, I thought: this is the first time in my life that I feel understood.' (26)

Finally, the adults were clear about the characteristics of effective support concerning interpersonal relations. Mainly the need for support with 'putting the theory into practice' was discussed.

'In school we have lessons in social skills. There we discuss various themes, such as friendships and making friends. These lessons last two hours and are purely theoretical. Consequently, I know how to make friends, but I can't put it into practice. On the one hand I am satisfied about those lessons because it's easy stuff for me; on the other hand I don't learn anything from those theoretical lessons. I really would like to learn how to become less timid.' (9)

DISCUSSION

The present study describes the support needs profile and the support experiences of 58 high functioning adults with ASD. Despite the amount of studies addressing the support needs and experiences of children with ASD and their parents (Bromley et al., 2004; Gabriels et al., 2001; Renty & Roeyers, in press; Sperry et al., 1999), to our knowledge, no research has conducted an in-depth examination of these topics in adults with ASD.

The first aim of the present study concerned the identification of support needs in adults with ASD. The main psychosocial outcome characteristics of the individuals who participated in our study were comparable to those found in other studies. Despite their intelligence and often good levels of functioning in other areas, few adults with high functioning ASD in our study reported living independently. More than half of the participants lived with their parents, approximately a quarter lived with professional support, and less than a quarter lived independently or with a partner. A similar distribution of outcome in living arrangement was found in a study conducted by Szatmari, Bartulocci, Bremner,

Bond, and Rich (1989) with more than three quarters of the participants living with support from parents or professionals. Other studies reported even higher proportions of adults with ASD living with support from either their family or professional services (Mawhood, Howlin, & Rutter, 2000; Rumsey, Rapoport, & Sceery, 1985; Venter, Lord, & Schopler, 1992). In close connection with the living arrangement, the CAN interviews revealed that more than three quarters of the adults reported a support need on the domain of preparing meals (Food) and Housekeeping.

Also the rates of gainful employment were lower than expected for individuals within the normal range of intelligence. Almost a third of the adults participated in a training programme. Approximately half of the individuals was employed: half of them held a competitive job, the others were engaged in sheltered, supported, or voluntary employment. More than a fifth of the participants held no job at all. Except for the study of Mawhood et al. (2000), our findings concerning employment outcome were less positive than in other studies. More persons were unemployed and less persons held a competitive job as compared to the participants in the studies of Rumsey et al. (1985), Szatmari et al. (1989), and Venter et al. (1992). Possible differences in access to supported employment and differences on social, political, and commercial factors may account for differences between our sample and those from other studies.

Next to support needs with respect to living and working circumstances, the CAN revealed that more than half of the adults with ASD has a support need with respect to Psychological Distress, ASD-specific Information, and administrative issues (such as Social Benefits and Household Administration). Support needs in the aforementioned areas reflect the well-known functional disabilities associated with ASD and underline the pervasiveness of the disorder.

The second aim of the present study was to identify met and unmet support needs of adults with ASD. On the one hand, support needs were most generally met for the areas requiring practical support (Housekeeping, Food, Accommodation, Social Benefits, and Household Administration). On the other hand, the areas of interpersonal relations (Company, Intimate Relationships, Sexual Expression) and psychosocial well-being (Psychological Distress, ASD-specific

Information, Safety to Self) had the highest proportion of unmet to total needs, suggesting either that these areas suffer from a relative neglect of professional supporters or that professionals are ineffective in meeting these support needs. Since previous research (Renty & Roeyers, 2005b) revealed that unmet needs in the areas of Company, Intimate Relationships, and ASD-specific Information are significantly associated with lower levels of quality of life, these unmet needs pose a major challenge to the formal and informal support network.

The third objective of our study was to describe the amount of received informal support and the amount of received and needed formal support. Our data indicate that the informal support network plays the most significant role in meeting the needs of the adult with ASD. Not surprisingly, the informal network mainly takes action when ‘instrumental’ or ‘practical’ support is called for (such as Food, Accommodation, Housekeeping, Transport, and Social Benefits). The formal support network mainly concentrates on psychological well-being (Psychological Distress and Psychotic Symptoms), Social Benefits, Information on ASD and ASD-specific Intervention, and Daytime Activities. In general, the participants reported a substantially higher degree of support needed than of support received from the formal support network. The amount of discrepancy between received and needed formal support was most apparent for the areas Company and Information on ASD and ASD-specific Intervention.

Finally, the fourth aim of our study was to describe the support experiences of adults with ASD. Qualitative analyses of the interviews revealed what the adults perceive as supportive resources that could be helpful in increasing the quality of their lives. Firstly, many adults commented on the difficulties they experienced with the diagnostic process. Although the diagnosis of ASD is relatively stable from age 2 onwards (Lord, 1995; Moore & Goodson, 2003), more than three quarters of the adults had been diagnosed above the age of 12, often after having consulted various combinations of professionals. This lengthy delay often means that the adults did not get the support they required during this difficult period. Moreover, the adults held strong opinions about essential characteristics of a good disclosure interview. These characteristics were: adequate and clear information on the diagnosis, emotional support, information on services and social benefits, and the opportunity for specific and ongoing post-disclosure support and counselling.

Similar findings were found in other studies examining parent's views on the disclosure interview concerning their child with ASD (Brogan & Knussen, 2003; Whitaker, 2002).

Secondly, the participants stated that effective support should be characterized by individualization, comprehensiveness, and flexibility. They consider it as very important that the formal and informal support network listens to and consults with them in order to act upon their personal preferences. Ruef and Turnbull (2002) came to similar conclusions in their study on perceptions of individuals with cognitive disabilities and/or autism on their lives and problem behaviour. Persons with disabilities should be the ones to determine the relevance of various intervention approaches and whether the defined outcomes are likely to improve their quality of life.

We recognize that the present study has several limitations. Firstly, it is important to be aware that, due to a selection bias, the sample may not be representative of the population of high functioning adults with ASD as a whole. Secondly, since the CAN assesses the subjective support needs of individuals, no absolute conclusions can be drawn with respect to the difficulties adults with ASD experience. Although some adults did experience many difficulties with respect to one or more areas of the CAN, they did not report a support need, for instance, because they were convinced that there was no formal or informal support available that could deal with their problems. Consequently, the reported frequencies of need may be an underestimation of the problems adults with ASD experience. Thirdly, although we attempted to account for our biases and expectations in the context of analyzing our data, it is possible that our perceptions uniquely influenced aspects of the investigation. To this end, it is important that other researchers replicate our study. Finally, we relied on self-report data only. Although we succeeded in putting the adult's perspective into focus by using self-report data only, future research should address the perceptions of the formal and informal support network too, in order to identify critical differences of opinion that may be the source of some unmet needs.

Notwithstanding these limitations, the findings of the present study have important implications for the informal support network, professional supporters,

and policy makers. Given the fact that most individuals with ASD achieve relatively low levels of independency and continue to require support from both the informal and the formal support network, it is important that support experiences of adults with ASD are systematically evaluated. The significant association of unmet support needs with lower levels of quality of life (Renty & Roeyers, 2005b) strengthens the emphasis that should be laid on individual and thorough assessment of these needs. The use of a formal assessment tool, such as the CAN, certainly facilitates the monitoring of (met and unmet) support needs.

Part III

THE PREDICTIVE VALUE OF FORMAL AND INFORMAL SUPPORT FOR THE QUALITY OF LIFE IN ADULTS WITH AUTISM SPECTRUM DISORDER

CHAPTER 5

QUALITY OF LIFE IN ADULTS WITH AUTISM SPECTRUM DISORDER: THE PREDICTIVE VALUE OF DISABILITY AND SUPPORT CHARACTERISTICS¹

ABSTRACT

Although the concept of quality of life has increasingly been used in the field of intellectual disabilities over the past 3 decades, the factors contributing to the quality of life of persons with autism spectrum disorder (ASD) have received relatively little attention. In this study, disability and support characteristics associated with variations in the level of quality of life among adults with ASD are identified using self-report measures. Fifty-eight high functioning adults with ASD participated in the study. The results of a multiple linear regression analysis revealed that support characteristics are related to quality of life in adults with ASD, whereas disability characteristics are not. The R^2 effect size (.620) was large and significant. The results reinforce the significance of an available supportive social network, and the importance of a substantial needs assessment and effective professional support.

¹ Renty, J., & Roeyers, H. (2005). Quality of life in adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Manuscript under editorial review in Autism.*

INTRODUCTION

In most recent years, the number of publications on adult outcome of high functioning persons with autism spectrum disorder (ASD) has grown rapidly. The findings mainly concentrate either on descriptive information regarding (unidimensional) outcome domains (such as living and working circumstances, psychiatric functioning, academic achievements, etc.) (e.g., Engström, Ekström, & Emilsson, 2003) or on the predictive value of variables related to outcome (e.g., language skills, social behaviour, and IQ) (e.g., Nordin & Gillberg, 1998; Venter, Lord, & Schopler, 1992). Howlin (2000) and Tsatsanis (2003) reviewed the literature on outcome for adults with high functioning autism or Asperger's Disorder and concluded that only a minority had received college or university education, lived (semi-)independently, had close, spontaneous friendships, was married, or had a paid job. The social and communicative impairments adults with ASD struggle with often give rise to lower social adaptive levels of functioning than what would be expected on the basis of their language skills and their -often excellent- cognitive abilities.

The most significant predictors of outcome in adults with ASD appear to be early communication skills and the level of intellectual functioning (Howlin, 2000). Howlin and colleagues (Howlin, Goode, Hutton, & Rutter, 2004) found that individuals with IQ scores above 70 were likely to demonstrate a more positive outcome. Furthermore, the authors suggested that, besides cognitive abilities, the fundamental deficits associated with ASD (e.g., the degree of stereotyped and ritualistic behaviour) may impact the outcome significantly and thus may go beyond the effect of a high level of intelligence.

Lord and Venter (1992) suggested that the availability of a supportive social network or a local support provision may also have a significant impact on outcome. Access to specialist and appropriate support provides these persons with more opportunities to live independently (Tantam, 2003), to find and hold a suitable job (Hurlbutt & Chalmers, 2004), to develop social relationships (Howlin & Yates, 1999), and to diminish psychological disorders that are often secondary to ASD (Tantam, 2000). Ruble and Dalrymple (1996) stressed the importance of research investigating the predictive value of environmental variables for outcome,

since these variables can be manipulated and are more responsive to intervention than within-person factors which tend to be less amenable to change.

Despite the number of outcome studies in high functioning adults with ASD, research has mainly focused on unidimensional outcome domains. Opposite that, the construct of quality of life represents a more comprehensive outcome measure, which is multidimensional and also takes into account subjective variables such as satisfaction and subjective well-being. Internationally, there is a broad consensus about the fact that the term quality of life refers to a set of factors composing personal well-being. Eight quality of life domains are distinguished: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights (Schalock, 2004). The conceptual model of quality of life has been supported by empirical research across several disciplines (Hughes & Hwang, 1996; Schalock et al., 2005).

Across a number of studies (e.g., Beadle-Brown, Murphy, & Wing, 2005; Felce & Perry, 2005; Otrebski, 2000), personal factors (e.g., level of adaptive functioning), environmental variables (e.g., perceived level of social support, current living and working circumstances), and provider characteristics (e.g., job satisfaction of professional supporters), have proven to be significant predictors of quality of life in persons with intellectual disabilities.

The aim of the present study was to determine the predictive value of disability and support characteristics for quality of life in adults with ASD. We hypothesized that support characteristics would explain a significant amount of variance in quality of life, over and above IQ and severity of autism.

METHOD

Sample

The sample of adults with ASD was drawn from two sources. Firstly, participants were recruited through advertisements in an ASD advocacy group newsletter and a newsletter of the Flemish user organization for ASD. Secondly, persons who participated in previous autism research at our laboratory were invited to take part in the present study. The final sample consisted of 58 adults with ASD, living in Flanders (Belgium). The adults in the study had to meet two criteria: 1) they all had to be in the normal range of intelligence, demonstrating a full scale IQ of 70 or more (assessed by the WAIS-III; Wechsler, 2000); and 2) they all needed a diagnosis by a multidisciplinary team of experienced clinicians and fulfilled established DSM IV-TR (APA, 2000) criteria for autism, Asperger's Disorder or PDD-NOS.

Measures

Quality of life

Quality of life was measured using the Quality of Life Questionnaire (QoL.Q; Schalock & Keith, 1993). The QOL.Q is a 40-item, widely used self-report scale administered in an interview format. Although the QOL.Q is initially designed to measure overall quality of life of persons with intellectual disabilities, the scale is also found suitable for persons with ASD (R. Schalock, personal communication, 20 November 2003). The instrument comprises of 4 subscales: Satisfaction (e.g., Do you have more or less problems than other people?), Competency/Productivity (e.g., Do you feel your work is worthwhile and relevant?), Empowerment/Independence (e.g., Who decides how you spend your money?) and Social Belonging/Community Integration (e.g., How satisfied are you with the clubs and organizations to which you belong?). Each subscale contains 10 items, scored on a three point Likert scale. Scores on the total QOL.Q range from 40 to 120 and a higher score represents a higher overall level of quality

of life. The QOLQ has good psychometric properties with a test-retest coefficient of .87 and with a Cronbach's Alpha coefficient of .90 for the total scale (Schalock & Keith, 1993). In the present sample, the Alpha coefficient was .85.

Disability characteristics

The degree to which an adult within the normal range of intelligence shows traits related to the autism spectrum was measured using the Autism-spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001; Ponnet, Roeyers, & Buysse, 2001). The AQ is a 50-item self-report questionnaire. Scores on the total scale range from 0 to 50, the higher the score on the AQ the more autism-related symptoms the person displays. Although Baron-Cohen and colleagues (Baron-Cohen et al., 2001) set the cut off score at 32+ for distinguishing persons who have clinically significant levels of autism specific traits, there are recent studies suggesting a cut off score of 26+ (Kurita, Koyama, & Osada, 2005; Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005). The instrument shows good psychometric properties (Baron-Cohen et al., 2001). The internal reliability of the total scale proved to be excellent in the present sample, with a Cronbach's Alpha coefficient of .91.

Support characteristics

Perceived informal support. The Interpersonal Support Evaluation List (ISEL; Cohen, Mermelstein, Kamarck, & Hoberman, 1985) was used to assess perceived availability of informal support. The items fall into four 10-item subscales: Tangible (perceived availability of material aid), Appraisal (perceived availability of someone to talk to about one's problems), Self-esteem (perceived availability of a positive comparison when comparing one's self to others), and Belonging (perceived availability of others one can do things with). A higher score on the ISEL represents a larger extent of perceived informal support (range 40-160). The internal reliability of the ISEL proved to be good with documented Cronbach Alpha's from .88 to .90. In the present sample the Alpha coefficient amounted to .91.

Received informal and formal support. The Camberwell Assessment of Need (CAN; McCrone et al., 2000; Phelan et al., 1995) surveys the subjective perception of support needs and received (informal and formal) support, administered in an interview format. The CAN follows an identical rating procedure for 22 need domains and each domain is evaluated in three sections. In the first section the interviewer rates the perceived support need of the client. If a need is recorded as being present, the second and third section are applied. In the second section (CAN-I) further information was asked to gain insight in current level of informal support (i.e. help from friends or relatives) (0 = none, 1 = low, 2 = moderate, 3 = high). The third section uses the same rating as the second one and focuses on the amount of formal support actually received (CAN-F) and the amount of formal support needed (CAN-FN). Summary informal and formal support scores are calculated by adding the support scores in respectively the second and third section over all 22 domains.

Although the CAN was initially designed to describe met and unmet needs of persons with psychiatric and intellectual disabilities, its use for persons with ASD has been introduced by Engström and colleagues (Engström et al., 2003). To test inter-rater reliability of the CAN, all transcribed interviews were rated by three independent raters. Intraclass correlation coefficients between summary scores of the three raters ranged from .95 to .97. In case of different ratings, all three interviewers discussed the situation in order to reach a consensus score.

Demographic characteristics

Demographic information was collected through a demographic information form including the person's birth date, gender, diagnostic information, education, employment, residential status, and marital status.

Statistical analysis

Descriptive measures were calculated for each instrument. Pearson's correlations and univariate analyses of variance (ANOVAs) were conducted to assess associations between demographic information and overall quality of life.

Factors predictive for quality of life were identified using hierarchical multiple regression analysis. The assumptions for linear regression analysis (normality, linearity, and homogeneity of variance) were fully met. Multicollinearity among predictor variables was suspected considering the large zero-order intercorrelation coefficients between some pairs of support variables and the average variance inflation factor being much higher than 1. Since multicollinearity among predictor variables makes it difficult to assess the individual importance of a predictor variable, the association between predictor variables of interest and quality of life were examined using Pearson's correlations. Finally, the association between quality of life and formal support discrepancy was examined for each area of the CAN. The level of formal support discrepancy was obtained by subtracting the level of received formal support from the level of needed formal support. Because the support discrepancy data were at the ordinal level and because there was a large number of tied ranks, non-parametric correlations (Kendall's Tau) were used.

RESULTS

Participant characteristics

Table 1 summarizes the demographical data of the participants. Our sample consisted primarily of men in early adulthood. Only a minority of the participants lived independently, was in mainstream employment, was married, or had an intimate relationship with a (heterosexual) partner.

A series of bivariate analyses yielded no significant effects of relevant demographic information, such as age, gender, education, living arrangement and intimate relationship on quality of life. Quality of life did differ in relation to daytime activities, i.e. those who were student or had any form of job had significantly higher quality of life scores than those who were unemployed ($F(1,57) = 30.63, p < .001$). This significant difference could be an artefact caused by the subscale Competence/Productivity in the Quality of Life scale, which takes into account the employment status of the person. However, even when the

concerning subscale was not included in the total quality of life score, this significant difference still existed ($F(1,57) = 4.920, p = .031$).

Table 1
Participant characteristics

	Adults with ASD ($n = 58$)
Chronological age	
<i>M</i> (<i>SD</i>)	28.34 (9.78)
Range	18-53
Gender	74% male
Diagnosis	
Autism	21%
Asperger's Disorder	34%
PDD-NOS	9%
ASD	36%
Education	
Elementary/high school	76%
College/university	24%
Current day activity (not mutually exclusive categories)	
Student	29%
Mainstream employment	28%
Supported/sheltered employment	19%
Day activity programme	5%
No work or school	24%
Current living circumstances	
Independently	10%
With partner	9%
With parents	55%
Supported/residential living	26%
Intimate relationship	
Single	67%
Intimate relationship with (heterosexual) partner	19%
Married/Cohabiting	9%
Divorced	5%

Disability and support characteristics

Table 2 presents the means, standard deviations, and ranges of scores on the disability and support measures.

Table 2
Means, standard deviations and ranges on disability and support measures (n = 58)

	<i>M (SD)</i>	Range
Disability measures		
Autism specific traits (AQ)	29.69 (10.33)	5 - 46
Full Scale IQ (WAIS-III)	103.09 (16.80)	70 - 139
Support measures		
Perceived informal support (ISEL)	110.16 (19.31)	71 - 152
Received informal support (CAN-I) ¹	12.53 (7.04)	0 - 27
Received formal support (CAN-F) ¹	6.91 (5.98)	0 - 24
Needed formal support (CAN-FN) ¹	9.05 (6.89)	0 - 26
Unmet formal support needs (CAN-U) ²	1.59 (1.78)	0 - 7

¹ The level of received and needed support measured by the CAN consisted of the sum of the scores on the 3-point scale over all 22 recorded support needs of the CAN (theoretical range 0 - 66)

² The number of unmet formal support needs measured by the CAN consisted of the number of domains in which a discrepancy between received and needed formal support was present (theoretical range 0 - 22)

With respect to perceived informal support, measured by the ISEL, additional information was asked about the sources of perceived social support. Participants reported counting on the support of their mother (78%), father (43%), siblings (69%), friends (76%), other family members (15%), and finally, their partner (9%).

Quality of life in relation to disability and support characteristics

A hierarchical multiple regression analysis was conducted to determine whether disability and support characteristics explained a significant amount of variance in quality of life after controlling for relevant demographic characteristics. Table 3 displays the results of the regression analysis.

Table 3
Results of a hierarchical multiple regression analysis investigating the predictive value of disability and support characteristics for quality of life

Block	Variable	R^2	R^2 Change	F Change
1. Demographic characteristics		.007	.007	0.206
	Age			
	Gender			
2. Disability characteristics		.106	.099	2.934
	FSIQ			
	AQ			
3. Support characteristics		.620	.514	16.592**
	ISEL			
	CAN-I			
	CAN-F			
	CAN-U			

Note. FSIQ, Full Scale Intelligence Quotient measured by the WAIS-III; AQ, Autism spectrum Quotient; ISEL, perceived social support measured by the ISEL; CAN-I, Received informal support measured by the CAN; CAN-F, Received formal support measured by the CAN; CAN-U, number of unmet formal support needs measured by the CAN

** $p < .001$

The eight variables entered into the equation in three different blocks were able to account for 62% of the variance in quality of life (56% adjusted), $F(8,57) = 10.01$, $p < .001$. Disability characteristics did not explain a significant amount of

variance in quality of life over and above demographic variables. Conversely, support characteristics accounted for 51% of the variance in quality of life over and above demographic variables and disability characteristics, F Change (4,57) = 16.59, $p < .001$.

The set of support characteristics was further explored in order to identify the support variables that are most strongly associated with overall quality of life. Pearson's correlations between support characteristics and quality of life revealed that neither received informal ($r = -.134$) nor received formal support ($r = -.090$) correlated significantly with quality of life, $ps > .30$. In contrast, perceived informal support was positively correlated with quality of life ($r = .552$, $p < .001$) and the number of unmet formal support needs was negatively associated with quality of life ($r = -.633$, $p < .001$). The support domains of the CAN in which a discrepancy between received and needed formal support was present were identified and the association with quality of life was examined using Kendall's correlation coefficients. A higher quality of life was significantly associated with less formal support discrepancy in the domains Accommodation ($r = -.221$, $p < .01$), Daytime Activities ($r = -.260$, $p < .01$), ASD-specific Information ($r = -.289$, $p < .01$), Company ($r = -.478$, $p < .001$), and Intimate Relationships ($r = -.315$, $p < .01$).

DISCUSSION

To our knowledge, the present study is the first empirical investigation examining outcome and predictors of outcome in high functioning adults with ASD, using the conceptual framework of quality of life. We hypothesized that support characteristics would explain a significant amount of variance in quality of life over and above disability characteristics.

An exploration of the unidimensional outcome domains of the participants confirms existing literature on the poor outcome of high functioning adults with ASD. Despite their intelligence and often good levels of functioning in other areas, more than three-quarters of the participants lived with their parents or with professional support. A similar finding of outcome in living arrangement was

reported in a study conducted by Szatmari and colleagues (Szatmari, Bartulocci, Bremner, Bond, & Rich, 1989). Other studies reported even higher proportions of adults with ASD living with support from either their family or professional services (Mawhood, Howlin, & Rutter, 2000; Rumsey, Rapoport, & Sceery, 1985; Venter et al., 1992). Also the rates of gainful employment were lower than expected for individuals within the normal range of intelligence. Approximately half of the individuals was employed: half of them held a mainstream job, the others were engaged in sheltered or supported employment, or in a day activity programme. More than a fifth of the participants held no job at all. Except for the study of Mawhood et al. (2000), our findings concerning employment outcome were less positive than in other studies. More persons were unemployed and less persons held a competitive job as compared to the participants in the studies of Rumsey et al. (1985), Szatmari et al. (1989), and Venter et al. (1992). Possible differences in access to supported employment and differences on social, political, and commercial factors may account for differences between our sample and those from other studies.

Quality of life

In contrast with past research, which mainly focused on unidimensional outcome domains and the predictive value of (stable) disability characteristics for outcome in adults with ASD, the present study focused on the multidimensional concept of quality of life and the predictive value of (changeable) environmental characteristics. The findings supported our hypothesis that support characteristics explain a significant amount of variance in quality of life over and above disability characteristics. The association between support characteristics and quality of life was further explored by means of Pearson's correlations.

On the one hand, with respect to informal support, our findings demonstrated that perceived informal support was significantly related to quality of life, whereas received informal support was not. Several authors (e.g., Hansson et al., 2003; Petito & Cummins, 2000; Walden, Pistrang, & Joyce, 2000) described the significant (positive) association of informal support with quality of life in persons with intellectual disabilities, persons with psychiatric disorders, or their

parents, often without making the distinction between perceived and received informal support. However, the literature on social support emphasizes the discrimination between these two constructs. Whereas perceived social support is conceptualized as a perception that one's network is ready to provide support and aid if needed, received social support is measured by the actual transfer of advice, aid, and affect through interpersonal networks (Wethington & Kessler, 1986). A systematic review of social support literature shows that, in correspondence with our results, personal well-being is more strongly linked to the perception that support is available than to the effects of actual supportive behaviors (Kessler & McLeod, 1985). Although Walden et al. (2000) and Hansson et al. (2003) did not expressly state which of the two concepts was used in their study, an analysis of their measures made clear it concerned hypothetically available and thus perceived support.

On the other hand, with respect to formal support, our findings demonstrated that the extent of received professional support was not associated with variations in quality of life. Previous studies in different populations emphasized the apparent lack of effect of formal support on personal well-being and quality of life (e.g., Duvdevany & Abboud, 2003; Seltzer & Krauss, 1989; Walden et al., 2000). In contrast, we found that the discrepancy between needed and received formal support was strongly associated with quality of life. Adults with high levels of quality of life reported less formal support discrepancy compared to their counterparts. Also this finding is consistent with earlier studies in different populations (Hansson et al., 2003; Slade, Leese, Taylor, & Thornicroft, 1999; Slade et al., 2004) in which an obvious negative association between unmet formal support needs and overall quality of life was found. Our findings do not only reinforce these previous studies, but provide the additional insight that quality of life is the most strongly associated with an unmet formal support need regarding accommodation, interpersonal relationships, daytime activities, and ASD-specific information.

Whereas support characteristics proved to be a significant predictor of quality of life, we found no evidence that IQ and autism specific traits contributed to the prediction of quality of life. Howlin and colleagues (Howlin et al., 2004) reported earlier that amongst individuals with an IQ above 70, variations in level of

intelligence are of little predictive value in terms of outcome. Despite their assumption that outcome in high functioning adults with ASD may be more related to the fundamental deficits characteristic for ASD, we found no evidence for a significant association between autism-specific traits and quality of life. Although the AQ appears to be a useful self-report instrument in identifying the extent of autistic traits (Baron-Cohen et al., 2001), further research based on other-report measures should be conducted to strengthen our findings.

Study limitations

Several limitations restrict the interpretations of our findings. Firstly, sampling techniques may limit generalization of the findings. The adults who voluntarily participated in our study may have particularly satisfying levels of quality of life. Moreover, the participants' average score on the AQ ($M = 29.69$) was rather low in comparison with the cut off score of 32+ set by Baron-Cohen et al. (2001). Although there are recent studies suggesting a cut off score of 26+ for the AQ (Kurita et al., 2005; Woodbury-Smith et al., 2005), it is possible that our sample consisted mainly of adults with better communication or social skills than other adults with ASD. Secondly, it should be taken into account that our data are based on self-report measures only, which may have caused inflated associations between the variables under study because of a shared method variance. The final limitation of this study concerns the cross-sectional research design, which only allows for ascertaining non-causal associations between support characteristics and quality of life. One cannot assume that support characteristics in our analysis directly cause the examined dimensions of quality of life. Higher levels of support, for example, may cause higher levels of quality of life, but increased quality of life may likewise expand perceived levels of informal support. It should be kept in mind that there may exist a constant interplay between the predictor and the criterion variables. To confirm that these relationships have a causal nature, more longitudinal research investigating changes in support characteristics and their association with changes in quality of life would be required.

Practical implications

Despite its limitations, the present study leads to a number of important practical implications. Firstly, the extent to which quality of life is found to be associated with support characteristics and the finding that quality of life is not determined by severity of disability lend empirical evidence to the social model of disability, in which disability is defined as a social pathology (Oliver, 1996; Race, Boxall, & Carson, 2005). This approach emphasizes that the extent to which one is 'disabled' is not only the result of factors residing in the individual but mainly of the interaction between the individual and the environment. Barnes, Mercer, and Shakespeare (1999) stressed the significance of social and material conditions as key factors for the individual's experience of disability. Our results underline the importance of this good person-environment fit.

Furthermore, given the significant association of quality of life with the number of unmet formal support needs, professional supporters should strive to meet all individual needs persons with ASD report. Therefore, there should be a greater emphasis on the assessment of met and unmet needs from the individual's viewpoint. Thorough needs assessment should be the professional's main tool for planning and evaluating interventions towards individuals with ASD. Since people with ASD often experience additional difficulties which are frequently but not universally associated with the core symptoms of ASD (Tantam, 2000), a thorough needs assessment would enable professional interveners to survey all met and unmet needs individually. Unmet needs require specific and systematic attention since professionals are often unaware of those inconspicuous needs, which are nonetheless substantially associated with lower levels of quality of life.

Finally, this study supports the significance of quality of life as a multivariate outcome measure. Though the conceptual framework of quality of life and its associated practical methodologies (such as Person Centered Planning) have largely found acceptance in disability literature and are often referred to by practitioners, its actual implementation with individuals with a disability occurs only gradually in Belgium. However, a methodology such as Person Centered Planning provides individuals with the opportunity to strengthen the supportive social network and to receive support that is completely tailored to the individual's

needs. Given the results of the present study, the significance of such quality of life-related methodologies for persons with ASD cannot be overestimated.

CHAPTER 6

INDIVIDUAL AND MARITAL ADAPTATION IN MEN WITH AUTISM SPECTRUM DISORDER AND THEIR SPOUSES: THE ROLE OF SOCIAL SUPPORT AND COPING STRATEGIES¹

ABSTRACT

The aim of the present study was to examine the predictive value of social support and coping for individual and marital adaptation in adult men with ASD and their spouses, based on the double ABCX model of adaptation. Twenty-one men with ASD and their spouses participated in the study and completed measures of stressor severity, social support, coping, and individual and marital adaptation. Bivariate analyses showed that each of the model components was related to individual and/or marital adaptation in men and women. Hierarchical regression analyses revealed that, after controlling for relevant demographics and stressor severity, informal support was a strong and unique predictor of individual and marital adaptation in both spouses (explained variance: 27-89%). Coping did not add to the prediction of adaptation. Clinical implications and limitations of the study are discussed.

¹ Renty, J., & Roeyers, H. (2005). Individual and marital adaptation in men with autism spectrum disorder and their spouses: The role of social support and coping strategies. *Manuscript submitted for publication.*

INTRODUCTION

Recent epidemiological studies report prevalence rates of autism spectrum disorder (ASD) as high as 60 to 70 per 10,000 live births (Fombonne, 2003). Various family and twin studies have documented on the significant genetic component of autism. Bailey, Phillips, and Rutter (1996) concluded in their review article that autism is the most strongly genetic of all multifactorial psychiatric disorders. The prevalence of autism in siblings of children with ASD is 2 - 8 % (Muhle, Trentacoste, & Rapin, 2004), which is substantially higher than in the general population. Twin studies also showed higher concordance rates among monozygotic twins compared to dizygotic twins (Folstein & Rosen-Sheidley, 2001; Fombonne, Bolton, Prior, Jordan, & Rutter, 1997; Piven, Palmer, Jacobi, Childress, & Arndt, 1997). Although there are no specific prevalence rates available for ASD in parents of children with the disorder, several studies suggest that parents (particularly fathers) often show a constellation of more subtle abnormalities, often referred to as 'the broader phenotype' (Rutter, 2000). This mainly includes social peculiarities (e.g., being aloof, having few peer friendships, few sharing of enjoyment or socio-emotional reciprocity) and communicative difficulties (e.g., odd conversation, pedantry in speech, difficulties in the organization of language) (Bailey, Palferman, Heavey, & Le Couteur, 1998).

Despite the increasing amount of literature on the broader autism phenotype in parents of children with ASD, no attention has been paid to the psychosocial and interpersonal functioning of parents with a disorder within the autism spectrum. Nonetheless, the symptoms associated with the broader phenotype of autism (such as social and communicative difficulties) concern particularly those aspects that are indispensable for the engagement in close interpersonal relationships (Karney & Bradbury, 1995). In addition, there is a growing body of evidence that families with a disabled or chronically ill family member experience higher stress levels and are more at risk of developing psychological difficulties than other families (e.g., Bromley, Hare, Davison, & Emerson, 2004; Pakenham, Samois, & Sofronoff, 2005). In the past, many studies have attempted to identify variables associated with successful adaptation in the members of such families. On the one hand, the symptomatology of a disorder has

been identified as a significant variable implicated in the outcome. For example, parents of a child with ASD appear to experience more stress than parents of children with an intellectual disability (e.g., Weiss, 2002) or cystic fibrosis (Bouma & Schweitzer, 1990). On the other hand, successful adaptation was found to be associated with the level of social support (Bromley et al., 2004), and psychological characteristics such as perceived self-efficacy (Hastings & Brown, 2002), locus of control (Henderson & Vandenberg, 1992), and coping strategies (Han, 2003; Taanila, Syrjälä, Kokkonen, & Järvelin, 2002). These variables are all more or less amenable to change, and are thus more relevant for family members and practitioners than more stable factors, such as the symptomatology of the disorder.

Many researchers have followed the latter approach and elucidated that individual and interpersonal outcomes following a severe stressor (e.g., a diagnosis of a disability) are the result of multiple factors interacting with each other. Among the most widely cited theoretical frameworks for conceptualizing adaptation to stressful events is the double ABCX model of McCubbin and Patterson (1983). According to this model, adaptation (XX) to a crisis is shaped by the following factors: the severity of the stressor (e.g., severity of the person's diagnosis) and the pile-up of demands (aA); the family resources (e.g., social support) (bB); the changes that families make to their definition of the situation to help understand the situation (cC); and the coping strategies employed (BC).

Research on adaptation in families of disabled or chronically ill family members is inconclusive regarding the impact of stressor severity and pile-up of demands (aA) on successful adaptation. Some studies have suggested that a more severe stressful event increases the vulnerability of a person to the negative effects of stress (e.g., Floyd & Gallagher, 1997; Keller & Honig, 2004), whereas other studies showed that families adapted successfully to the presence of a disability or chronic illness in their family, irrespective of the severity of the disorder. The latter studies have demonstrated that other variables such as family resources and coping strategies have more significance in terms of successful adaptation than stressor severity (Bristol, 1987; Kazak, 1986).

One of the most important family resources (bB) is social support (McCubbin & Patterson, 1983). A sizeable body of literature suggests that social support has a strong positive mediational effect on personal and family adaptation (e.g., Bromley et al., 2004; Holland & Holahan, 2003; Weiss, 2002). Although the literature on social support emphasizes the discrimination between received social support (= actual transfer of support) and perceived social support (= perceived availability of a supportive social network), it is remarkable that studies using the double ABCX model often neglect this distinction. Most studies examine the significance of either the amount of received support or the level of perceived support. Although a systematic review of social support literature shows that the perception that support is available is most strongly linked to personal well-being (Kessler & McLeod, 1985), studies using the ABCX model have established the significant impact of both received (e.g., Ostberg & Hagekull, 2000) and perceived social support (e.g., Tak & McCubbin, 2002). With respect to the source of social support, existing research has established the powerful buffering effect of spousal support (e.g., Bristol, Gallagher, & Schopler, 1988; Herman & Thompson, 1995; Saloviita, Italinna, & Leinonen, 2003) and of support from family, friends, and acquaintances (e.g., Saloviita et al., 2003; Trivette & Dunst, 1992). In contrast, the stress ameliorating impact of formal sources of support is more equivocal. Some studies found a strong relation between the level of received formal support and adaptation (e.g., Bristol, 1984; Honig & Winger, 1997), while others found no evidence for an association between these two variables (e.g., Saloviita et al., 2003; White & Hastings, 2004).

Coping (BC) refers to the cognitive and behavioural efforts family members employ to reduce or manage the demands on the family system (McCubbin & McCubbin, 1993). Coping strategies are considered of critical importance in determining whether a stressful event will result in adaptational or maladaptational outcome. Research findings suggest that the use of active, problem-focused coping strategies (e.g., positive reappraisal) is more often associated with successful adaptation (e.g., Endler, 1997). The reliance on passive, avoidant coping strategies (e.g., distancing) can be appropriate as first reaction to a stressor, but are usually not helpful in the long term when dealing with a chronic stressor (Pakenham et al., 2005).

Adaptation in families of children with ASD has been well documented in literature, but outcome in parents with ASD and their spouses has not received adequate attention. The present study focuses on the predictive value of stressor severity, received and perceived social support, and coping strategies for individual and marital adaptation as perceived by adult men with ASD and their spouses. It was hypothesized that better individual and marital adaptation would be positively related to the level of social support and the use of problem-focused coping strategies, and inversely related to autism-specific traits and the use of avoidant coping strategies.

METHOD

Participants

The couples for this study were recruited through advertisements in an ASD advocacy group newsletter and a newsletter of the Flemish user organization for ASD. Several criteria were set forward to be eligible to take part in the study: (1) the male spouse of the couples had to fulfil established DSM IV-TR (APA, 2000) criteria for autism, Asperger's Disorder or PDD-NOS; a formal diagnosis of ASD, given by a multidisciplinary team of experienced clinicians, was required; (2) the couples had to be married or cohabiting for at least one year; and (3) the couples had to have at least one child under the age of 18, who resided at home. Twenty-one couples participated in the present research. The men ranged in age from 35 to 54 years ($M = 43.52$, $SD = 4.98$), the women also ranged in age from 35 to 54 years ($M = 42.01$, $SD = 5.25$). A paired sample t-test revealed no significant difference between the age of the men and women. Of the couples, 91% was married and 9% cohabited. The length of the relationship ranged from 10 to 25 years ($M = 15.55$, $SD = 4.41$). Socio-economic status was assessed by the Hollingshead Four Factor Index (Hollingshead, 1975). There were 9 couples in Classes I-III (lower socio-economic classes) and 12 couples in Classes IV-V (upper socio-economic classes). Almost all men (86%) were employed full-time. Of the women, 38% was employed full-time, 48% was employed half-time and 14% was not employed. Paired sample t-tests revealed no significant differences on

years of education and employment status between men and women. The median annual family income was 30,000 € - 39,999 €. The number of children in the family ranged from 1 to 6 ($M = 2.48$, $SD = 1.33$).

Measure

Autism-specific traits

The degree to which the parent with ASD shows traits related to the autism spectrum, was measured using the Autism-spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001; Ponnet, Roeyers, & Buysse, 2001). The AQ is a 50-item questionnaire, falling into 5 subscales: Social Skills, Attention Switching, Attention to Details, Communication, and Imagination. Scores on the total scale range from 0-50, the higher the score on the AQ the larger the extent of autistic traits shown by the person. In the present study, the AQ was used as a self-report measure for the men and as an other-report measure for their spouses. The instrument shows good psychometric properties (Baron-Cohen et al., 2001). The internal consistency of the total scale proved to be satisfactory in the present sample, with a Cronbach's Alpha coefficient of .78 for men and .70 for women.

Social support

Perceived social support. A source-specific version of the Social Provisions Scale (SPS; Cutrona & Russell, 1987) was administered to evaluate perceived social support from two sources: the spouse on the one hand (SPS-S) and family, friends, and acquaintances on the other hand (SPS-F). The scale comprises of 24 items with a 4-point Likert scale and has six subscales: Reliable Alliance, Guidance, Social Integration, Attachment, Reassurance of Worth, and Opportunity to Provide Nurture. Higher scale scores indicate higher levels of perceived social support. Reliability for the scales ranges from .87 to .91 across a range of populations (Cutrona & Russell, 1987; Russell & Cutrona, 1991). In the present sample, the Cronbach's Alpha for the SPS-S was .93 for men and .88 for women. Regarding the SPS-F, the Alpha coefficient was .93 for men and .92 for women.

Received social support. To assess the extent of received support from the social network, a source-specific version of the Inventory of Social Supportive Behaviors (ISSB; Barrera, Sandler, & Ramsey, 1981) was used. The questionnaire was administered with respect to received support of the spouse on the one hand (ISSB-S) and received support of the family, friends, and acquaintances on the other hand (ISSB-F). The scale is a 40-item self-report measure rated on a 5-point scale. Higher scores suggest more received social support. The internal consistency has been consistently above .90 across different studies (e.g., Barrera, 1981; Barrera et al., 1981; Cohen & Hoberman, 1983). In the present sample, the Cronbach's Alpha for the ISSB-S was .91 for men and .93 for women. Regarding the ISSB-F, the Alpha coefficient was .95 for men and .96 for women.

Formal support and formal support needs

A part of the Camberwell Assessment of Need (CAN; McCrone et al., 2000; Phelan et al., 1995) was used to survey the subjective perception of formal support needs and the extent of received formal support. The CAN was administered in an interview format with both spouses. In contrast to the original CAN which assesses support needs and received formal and social support on 22 life domains, its present use was limited to received and needed formal support on 5 life domains: Daily Activities, Information on ASD and ASD-Specific Interventions, Psychological Distress, Intimate Relationship, and Child Care. The current and needed levels of formal support are rated on a 4 point-scale (0 = *none*, 1 = *low*, 2 = *moderate*, 3 = *high*). Scores on both scales range from 0 - 20, the higher the score on the scale the larger the extent of respectively needed and received formal support.

Coping strategies

The Ways of Coping Questionnaire (Lazarus & Folkman, 1984) measures eight coping strategies on 66 items with a 4-point Likert-format scale (0 = *not used*, 1 = *used somewhat*, 2 = *used quite a bit*, 3 = *used a great deal*). Participants were asked to think about a highly stressful situation involving the spouse with ASD. The questionnaire provides scores on the following coping strategy scales:

Confrontive Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem Solving, and Positive Reappraisal. In correspondence with previous studies (e.g., Holland & Holahan, 2003), the individual coping scales were assigned to either an Approach Coping Strategy composite (ApCS) or an Avoidance Coping Strategy composite (AvCS). The scales Confrontive Coping, Seeking Social Support, Planful Problem Solving, and Positive Reappraisal were assigned to ApCS composite, whereas the scales Distancing, Self-Controlling, Accepting Responsibility, and Escape-Avoidance were assigned to AvCS.

Folkman and Lazarus (1988) reported Cronbach's Alpha coefficients from .61 to .79 for the subscales. In the present study, 3 items (items 14, 33 and 43) were removed to improve the internal consistency of the subscales. Further reliability tests were conducted on the remaining items. The Cronbach's Alpha for the ApCS was .82 for men and .87 for women. Regarding the AvCS, the Alpha coefficient was .64 for men and .78 for women.

Individual adaptation

The Symptom Checklist-90 (SCL-90; Arrindell & Ettema, 1986; Derogatis, 1977) is a widely used 90-item self-report questionnaire used to assess psychological distress. Each item is rated on a 5-point scale ('not at all' to 'extremely') to indicate the severity of the symptom over the past week. Next to the Global Severity Index (GSI), which provides an index of overall psychological distress, the subscales of the Dutch version of the SCL-90 assess 8 clusters or primary symptom dimensions: Agoraphobia, Anxiety, Depression, Somatization, Insufficiency of Thought and Behaviour, Interpersonal Sensitivity, Hostility, and Insomnia. A higher score reflects a higher level of psychological distress. Alpha coefficients for the subscales range from .73 to .92 (Arrindell & Ettema, 1986). In the present sample, Cronbach's Alpha for the total scale was .98 for men and .97 for women.

Marital adaptation

Marital adaptation of both parents was measured by the Dyadic Adjustment Scale (DAS; Spanier, 1976). The DAS is a 32-item self-report questionnaire with four subscales: Dyadic Consensus (13 items), Dyadic Satisfaction (10 items), Dyadic Cohesion (5 items), and Affectional Expression (4 items). Summed scores on these four scales indicate overall Dyadic Adjustment, with higher scores reflecting better marital adaptation. Spanier (1976) reported an overall scale reliability of .96. In the present sample, Cronbach's Alpha for the total scale was .95 for men and .91 for women.

RESULTS***Differences between men and women for the perception of autism-specific traits and for the perception of support and coping strategies***

Table 1 displays the group differences between men and women on the perception of the degree of autism-specific traits of the male spouse with ASD and on the perception of support and coping strategies.

In general, women perceived more autism-specific traits than their husbands (M women = 37.52, M men = 32.90). With respect to support variables, there were significant differences between men and women on perceived social support from family, friends, and acquaintances on the one hand and on received social support from the spouse on the other hand. These group differences were in the direction of women perceiving more social support from the family, friends, and acquaintances and receiving less spousal support than their husbands.

With respect to coping strategies, group differences were found for neither the Approach nor the Avoidance Coping Strategy composites.

Table 1
Group differences on the perception of autism severity of the men with ASD and on informal support, formal support, and other coping strategies

Perception of ...	Men <i>M (SD)</i>	Women <i>M (SD)</i>	<i>t</i> (20)	<i>p</i>
Autism severity				
AQ	32.90 (6.30)	37.52 (4.71)	-3.73	.001
Informal support				
SPS-S	66.24 (10.77)	63.90 (9.57)	1.30	.207
SPS-F	58.38 (11.40)	71.19 (9.09)	-4.61	.000
ISSB-S	87.43 (24.78)	72.57 (21.91)	2.32	.031
ISSB-F	59.60 (20.14)	69.55 (22.21)	-1.54	.139
Formal support				
CAN - Received	3.52 (1.97)	2.95 (1.69)	2.03	.055
CAN - Discrepancy	1.90 (1.51)	1.48 (1.47)	1.14	.267
Coping strategies				
WOC-ApCS	50.19 (9.94)	54.48 (12.73)	-1.39	.180
WOC-AvCS	44.29 (6.86)	41.52 (8.42)	-1.31	.204

Note. SPS-S, Perceived social support from the spouse; SPS-F, Perceived social support from family, friends, and acquaintances; ISSB-S, Received social support from the spouse; ISSB-F, Received social support from family, friends, and acquaintances; CAN – Received, Received formal support; CAN – Discrepancy, Discrepancy between received and needed formal support; WOC-ApCS, Approach Coping Strategy composite of the Ways of Coping Questionnaire; WOC-AvCS, Avoidance Coping Strategy composite of the Ways of Coping Questionnaire

Differences between men and women for individual and marital adaptation

To test differences between men and women on the perception of individual and marital adaptation, paired sample t-tests were performed (see Table 2).

Table 2
Group differences on the perception of individual and marital adaptation

Perception of ...	Men <i>M (SD)</i>	Women <i>M (SD)</i>	<i>t</i> (20)	<i>p</i>
Individual adaptation (SCL-90)	204.00 (65.89)	147.95 (46.08)	3.39	.003
Agoraphobia	12.39 (6.70)	7.90 (1.58)	3.08	.006
Anxiety	20.62 (8.30)	15.19 (6.76)	2.59	.018
Depression	39.00 (13.63)	30.81 (12.00)	2.07	.052
Somatization	23.48 (8.24)	20.10 (8.76)	1.73	.099
Insufficiency of Thought and Behaviour	25.19 (8.27)	17.10 (8.19)	3.19	.005
Interpersonal Sensitivity	45.05 (15.41)	28.67 (9.70)	4.36	.000
Hostility	12.71 (5.65)	8.86 (2.71)	2.97	.008
Insomnia	6.71 (2.74)	6.57 (3.97)	0.13	.894
Marital adaptation (DAS)	93.81 (20.45)	90.14 (18.49)	1.11	.282
Dyadic Consensus	42.33 (8.16)	41.86 (8.42)	0.26	.800
Dyadic Satisfaction	32.43 (7.08)	30.33 (7.64)	1.59	.127
Dyadic Cohesion	12.90 (5.06)	11.52 (3.91)	1.52	.143
Affectional Expression	6.14 (2.43)	6.43 (2.73)	-0.60	.553

Group differences between men and women were found on the perception of overall individual adaptation and on the subscales Agoraphobia, Anxiety, Insufficiency of Thought and Behaviour, Interpersonal Sensitivity, and Hostility. In general, men experienced more psychosocial problems than their wives. With respect to the perception of marital adaptation, no significant differences were found between both groups.

Prediction of individual and marital adaptation

Bivariate associations between the ABCX model predictors (autism-specific traits, social support, and coping) on the one hand and individual and marital adaptation on the other hand were explored using Pearson's correlations, for both men and women.

With respect to the men (see Table 3), the analyses revealed that less perceived social support from family, friends, and acquaintances was related with more psychosocial distress. Marital adaptation was significantly associated with more received and perceived social support from the spouse and from family, friends, and acquaintances. With regard to coping, a significant association was found between the AvCS composite and individual adaptation, such that more avoidance coping was associated with more psychosocial distress. Marital adaptation in men was not related to any coping strategy.

Table 3
Pearson's correlations between ABCX model predictors and individual and marital adaptation in men

Predictor variable	Individual adaptation (SCL-90) ¹	Marital adaptation (DAS) ²
AQ	.269	-.102
SPS-P	-.205	.830**
SPS-F	-.654**	.831**
ISSB-P	-.139	.445*
ISSB-F	.003	.585**
CAN - Received	.223	-.190
CAN - Discrepancy	.337	.038
WOC-ApCS	.182	-.050
WOC-AvCS	.445*	-.153

¹ Higher scores on the SCL-90 suggest higher levels of psychosocial distress, and thus lower levels of individual adaptation

² Higher scores on the DAS suggest higher levels of marital adaptation

With respect to the women (see Table 4), individual adaptation was strongly related to received social support from family, friends, and acquaintances, such that women with higher levels of psychosocial distress received more support. Marital adaptation of the women was inversely related to the degree of autism-specific traits of their husband, while perceived and received support from their spouse were positively related to marital adaptation. Regarding the coping strategies, a significant positive relation was found between the AvCS composite and psychosocial distress. Marital adaptation of the women was not related to any coping strategy.

Formal support variables were associated with neither individual nor marital adaptation in men and women.

Table 4
Pearson's correlations between ABCX model predictors and individual and marital adaptation in women

Predictor variable	Individual adaptation (SCL-90)	Marital adaptation (DAS)
AQ	.240	-.457*
SPS-S	.126	.779**
SPS-F	.365	-.002
ISSB-S	.032	.464*
ISSB-F	.677**	-.355
CAN – Received	-.049	.039
CAN - Discrepancy	.381	-.433
WOC-ApCS	.304	.146
WOC-AvCS	.518*	.135

Hierarchical multiple regression analyses were performed to determine the impact of the social support and coping variables on individual and marital adaptation respectively, after controlling for the degree of autism-specific traits. Separate regressions were performed for men and women. Preliminary analyses were conducted to determine whether the predictor and criterium variables varied as a function of demographic information. Pearson's correlations revealed that

socio-economic status was related with individual adaptation in men ($r = -.440, p = .046$). Other demographic characteristics (such as age, years of marriage, and number of children) were not significantly associated with any predictor or criterium variables. Socio-economic status was entered as a covariate in the regression analysis that predicted individual adaptation in men.

Considering the small sample size, only those support and coping variables that were related to respectively individual and marital adaptation at the bivariate level were included as predictors in the hierarchical multiple regression analyses. The ABCX model determined the order of entry of the predictor variables: on step 1, relevant demographic variables were entered, the severity of the stressor was entered on step 2, support variables on step 3 and coping variables on step 4. Collinearity diagnostics were performed using variance inflation factors (VIF). No multicollinearity was evident since the VIF for the predictors ranged between 1.06 and 3.07 (<10) (Cohen, Cohen, West, & Aiken, 2003). Table 5 displays the results of the hierarchical multiple regression analyses.

All four regression models were significant and the explained variance ranged between 50% and 90%. After controlling for the effects of demographic information and the degree of autism-specific traits, social support accounted for a significant amount of variance (27% - 89%) in individual and marital adaptation in both spouses. On the other hand, coping strategies failed to explain additional variance in adaptation over and above autism-specific traits and social support.

Table 5
Results of hierarchical multiple regression analyses investigating the predictive value of autism-specific traits, social support, and coping for individual and marital adaptation in men with ASD and their spouses

Predictors	Men				Women			
	Individual Adaptation		Marital Adaptation		Individual Adaptation		Marital Adaptation	
	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Demographics								
SES	.193*	-.399*						
Autism severity	.118		.010		.057		.209*	
AQ		.247		.205		-.124		-.124
Informal support	.272**		.894***		.407**		.412**	
SPS-S				.622**				.753**
SPS-F		-.427*		.560**				
ISSB-S				-.137				-.048
ISSB-F				.008		.608*		
Coping strategies	.067				.032			
AvCS		.289				.222		
Total R²	.650		.904		.497		.621	
Total F	$F(4,16) = 7.41^{**}$		$F(5,15) = 28.38^{***}$		$F(3,17) = 5.60^{**}$		$F(3,17) = 9.28^{**}$	

* $p < .05$; ** $p < .01$; ***, $p < .001$

DISCUSSION

To our knowledge, the present empirical study is the first investigating adaptation and predictors of successful adaptation in adult men with ASD and their spouses, using the conceptual framework of the ABCX model (McCubbin & Patterson, 1983). The prediction that adaptation would be associated with higher levels of (informal) social support and with lower levels of avoidance coping, was largely supported at the bivariate level. Unexpectedly, formal support variables, approach coping strategies and stressor severity (except for marital adaptation in women) were unrelated to adaptation.

Several patterns emerged over the four regression models tested to examine the predictive value of the double ABCX model components for successful individual and interpersonal adaptation of adult men with ASD and their spouses.

Firstly, stressor severity was unrelated to individual adaptation in both men and women and to marital adaptation in men. It is possible that other variables reflecting the pile-up of demands caused by the initial stressor (e.g., financial charges, organizational workload, parenting stress) may have more significance in terms of adaptive or maladaptive outcome in both men and women. Several studies (e.g., Han, 2003; Lavee, McCubbin, & Patterson, 1985) reported on the fact that the effect of the pile-up of demands on adaptation is stronger than the effect of the initial stressor. On the other hand, the degree of autism-specific traits proved to be related to marital adaptation in the spouses of men with ASD. Women whose husband showed less autism-specific traits reported higher levels of marital satisfaction. However, the negative effect of stressor severity on marital adaptation was mediated by spousal support. In particular, it was the perceived spousal support that acted as an important buffer for the demands of living with a partner with ASD.

Secondly, at the multivariate level, social support from the informal network was related to both domains of adaptation in men and women. The results were not univocally in the direction of one source of support or one dimension of support (received/perceived) having more impact on adaptation than the other one.

Although individual adaptation was significantly associated with support from family, friends, and acquaintances in both men and women, differences between both groups were found regarding the significance of received versus perceived support on the one hand, and with respect to the direction of the association on the other hand. Better individual adaptation in men was associated with more perceived social support from family, friends, and acquaintances, whereas more psychosocial distress in women was related with more support received from this source. Although perceived social support is generally considered as a stronger predictor of personal well-being than received social support (Kessler & McLeod, 1985) and although we expected social support to be positively related to adaptation, it may be that the latter finding is primarily attributable to the attempt of family friends, and acquaintances to satisfy the support needs of women with high levels of psychological distress. However, longitudinal data are necessary to sort out the direction of the association between received support from family, friends, and acquaintances and psychosocial distress in women.

Furthermore, the lack of a significant association between spousal support and individual adaptation in both men and women warrants further attention. A large amount of literature on social support focuses on the significance of spousal support for individual adaptation to stressful events (Coyne & Downey, 1991). However, since we did not find any significant association between both variables in our study, it is possible that individual well-being in couples with one spouse having a social and communicative impairment depends more on other variables such as personality traits, self-esteem, appraisal of the stressor, positive events, etc. Future research should examine the role of these and other potentially relevant variables for individual adaptation in men with ASD and their spouses.

Marital adaptation was significantly associated with perceived and received spousal support in both men and women. This finding is consistent with prior research in couples suggesting that spousal support is an important interpersonal domain in marriage that contributes to the relationship quality (e.g., Pasch & Bradbury, 1998). Furthermore, received and perceived support from family, friends, and acquaintances were significantly related with marital adaptation in men.

Thirdly, we found no evidence that formal support from professionals and services was related to individual and marital adaptation in men with ASD or their spouses. The lack of an association between the amount of formal support and improved well-being was also found in other studies (e.g., Renty & Roeyers, 2005b; White & Hastings, 2004). Though Renty and Roeyers (2005b) found a significant association between formal support discrepancy and outcome in high-functioning adults with ASD, this association was not found in the present sample of married adults. The limited number of formal support needs of the present sample probably accounts for the reduced importance of both formal support variables in terms of individual or interpersonal outcome.

Finally, the prediction that coping would be related to better adaptation was partially supported at the bivariate level. The use of avoidance coping strategies was related with lower levels of individual adaptation in both men and women, but the prediction that approach coping strategies would be related to better adaptation was not supported. On the one hand, the latter finding may be due to the fact that the WOC failed to tap particular approach coping strategies associated with having (a spouse with) ASD. On the other hand, it is possible that the actual use of approach coping strategies is less effective in the context of living with (a spouse with) ASD. Other studies investigating adaptation in parents of children with ASD also failed to find a significant association between problem-focused coping strategies and adaptation (e.g., Bundy, 1996; Pakenham et al., 2005).

It is important to note some of the limitations which are inherent to the present study. Firstly, since the population of parents with a formal diagnosis of ASD is small, we experienced many difficulties in finding a sample of reasonable size to take part in the present study. The present sample was rather small and therefore, our results lack statistical power. In addition, the reliance on a non-random sample recruited through advertisements may have resulted in a sample that is not representative for the target population. Therefore, the generalizability of the findings may be limited. Thirdly, the use of the AQ as other-report measure has never been described before. Although both the men with ASD and their spouses obtained respectively self- and other-report scores that were reasonably high, the male spouses reported significantly less autism-specific traits than what

their spouses perceived. Since some items of the AQ may be difficult to judge for other persons than the ones with ASD (e.g., some items from the subscale Imagination), it is possible that the high scores of the female spouses reflect in part the familiarity with the characteristics of ASD, more than the actual symptoms as shown by their spouses. Additional research should determine whether the identification of autism-specific traits by persons other than the individual with ASD is related to one's knowledge of the core symptoms of ASD. Fourthly, given the cross-sectional research design, we were not able to determine causal relations between the variables under study. Longitudinal data would be necessary to investigate the process of adaptation over time and to ascertain the causal relation between the variables under study. It is intuitively compelling to suggest that more spousal support leads to better marital adaptation. However, our cross-sectional data do not rule out the alternative direction of the causal relation, that in happier marriages spouses are more apt to support each other. Finally, the data resulted from questionnaires only. Response bias and inflated associations between variables resulting from a shared method variance may have affected our findings.

Despite these limitations, the findings of this study yield some important clinical implications. Traditionally, there has been an emphasis on treatment and intervention towards the person with a disability, through the use of behaviour management techniques, communication and social skills training, etc. According to our study, autism severity is rather of limited importance to the prediction of individual and marital adaptation. Opposite that, informal support proved to have an important main or mediating effect on individual and marital adaptation in both the men with ASD and their spouses. On the one hand, interventions should be geared to the expansion or strengthening of the supportive informal network of families coping with ASD. On the other hand, support training for both spouses should be incorporated into existing marital programmes, since spousal support proved to be a strong and unique predictor of marital adaptation in men with ASD and their spouses. Support training involves that both spouses are taught how to respond effectively when their partner is experiencing individual or interpersonal difficulties and how to best convey their own difficulties so as to solicit effective support from their partner (Cutrona, 1996; Pasch & Bradbury, 1998).

The present study was limited to male parents with ASD and their spouses in order to control for extraneous variability. Future research should elucidate whether our findings are generalizable to couples without children and, as far as such sample can be identified, to couples with the female spouse having ASD. Furthermore, the inclusion of a matched control group of couples without disabilities would enable us to understand the unique difficulties experienced by couples with one spouse with ASD.

GENERAL DISCUSSION

The main aim of this doctoral research was to investigate the quality of support for persons with ASD and the predictive value of formal and informal support for the quality of life of these individuals. In this general discussion, an integrated overview of the main findings is presented, and their theoretical, clinical, and policy implications are discussed. Finally, limitations of the present dissertation and directions for further research are formulated.

INTEGRATION OF THE MAIN FINDINGS

The studies in the present dissertation aimed at investigating the quality of support for persons with ASD and the predictive value of support for the quality of life of these individuals. In the past, the emphasis of quality research has particularly been laid on the evaluation of support characteristics (program input, process, and output), rather than on the short- and long-term outcomes of support, which are more related to the quality of life of individuals (Schalock & Bonham, 2003). Whereas the first major theme of the present dissertation explicitly focused on the quality of support for persons with ASD (in particular on the input and process component of Schalock and Bonham's (2003) Program Logic Model), the second and the third theme reported on respectively the short- and long-term outcomes of support, and as such principally targeted the quality of life of persons with ASD. In the following, the discussion of the main findings will be organized around the three major themes of this dissertation.

The quality of support in Flemish schools and services for persons with ASD

Ever since the first epidemiological studies in the mid 1960s, a considerable increase in the prevalence of ASD has been observed (Fombonne, 2003). Whereas researchers have mainly focused on the potential explanations underlying this finding – and concluded that the increasing prevalence is most probably due to the broader diagnostic criteria and improvements in the identification of ASD – (e.g., Croen, Grether, Hoogstrate, & Selvin, 2002; Gernsbacher, Dawson, & Goldsmith, 2005; Wing & Potter, 2002), little attention has been paid to the consequences of this increase for organizations accountable for the provision of education and support adapted to the specific needs of persons with ASD. Nevertheless, the increasing number of persons identified with ASD has a considerable effect on the accessibility and the quality of these organizations (Ruble, Heflinger, Renfrew, & Saunders, 2005).

As for Flanders, both the service providers and the consumers reported on difficulties regarding the accessibility of appropriate education and support [see Chapters 1 - 4]. These difficulties of access were caused by waiting lists, requisites for admittance imposed by ASD-specific organizations (such as a formal diagnosis of ASD), and a limited supply of specialist schools and services for persons with ASD. Next to these causes of limited accessibility which are more or less directly associated with the number of persons with ASD seeking appropriate support, parents of children with ASD as well as adults with ASD complained of the non-transparency of the Flemish support system for persons with a disability. However, given the increasing empirical evidence that appropriately targeted interventions improve outcome in persons with ASD, accessing ASD-specific support as smoothly and quickly as possible is of the utmost importance (National Research Council, 2001). Along with predictability and an emphasis on the development of communication skills, individuals with ASD should be enrolled in programmes as early as possible (Dawson & Osterling, 1997; Howlin, 1998; Koegel, 2000; Rogers, 1998). In addition, there is a consensus that persons with ASD have specific support needs, even in pre-school, in terms of content and delivery of the curriculum/intervention and the structure and organization of the environment. It is generally acknowledged that these needs differ from those of children with general developmental delay (Charman & Baird, 2002). The need for an adapted support approach for persons with ASD is not merely expressed by researchers. Our findings in Chapter 3 and 4 revealed that also parents of children with ASD and adults with ASD prefer ASD-specific support over unspecialized support.

However, the findings of Chapter 1 and 2 demonstrated that the quality of the support delivered in Flemish schools and services was capable of improvement. Less than half of the organizations serving persons with ASD claimed to adapt the programme to the specific support needs of these individuals. Both Chapter 1 and 2 of this dissertation tried to identify factors that were associated with the presence of an ASD-specific approach in the organization. Whereas Chapter 1 focused on differences between schools with and without an ASD-specific approach in terms of the presence of areas of effective practice for persons with ASD (such as alternative communication means, individualization, parental involvement, etc.), Chapter 2 brought the significance of the number of service users with ASD under

attention. This focus on different factors associated with the presence of an ASD-specific approach in respectively Chapter 1 and 2 hindered us from drawing general conclusions about the significance of these factors over both educational and service provisions. Therefore, additional analyses were conducted on the data of respectively the schools and services. The analyses confirmed on the one hand that the presence of several areas of good practice for students with ASD was reflected in the number of students with ASD registered in the school. A higher number of students with ASD was found in schools having adopted the following areas of good practice for persons with ASD: individualization ($F(1,180) = 24.60, p = .000$), the use of a specialized curriculum (reflected by functional assessment of problem behaviour ($F(1,126) = 4.79, p = .030$), instruction in social and engagement skills ($F(1,126) = 3.14, p = .079$), training in leisure skills ($F(1,126) = 8.27, p = .005$), etc.), the use of alternative communication means ($F(1,179) = 6.62, p = .011$), the presence of physical adaptations in the classroom ($F(1,179) = 28.93, p = .000$), the opportunity to follow ASD-specific training ($F(1,192) = 17.98, p = .000$), parental involvement ratings ($r = .200, p = .007$), etc. On the other hand, the conclusions drawn from the analyses in the sample of schools [Chapter 1] were likewise applicable to the services examined in Chapter 2. Services claiming to have an ASD-specific approach differed from services without a specialized approach with respect to the presence of individualized support ($\chi^2(1) = 10.42, p = .001$), functional assessment of problem behaviour ($\chi^2(1) = 5.83, p = .011$), instruction in social and engagement skills ($\chi^2(1) = 15.30, p = .000$), training in leisure skills ($\chi^2(1) = 20.21, p = .000$), the use of alternative communication means ($\chi^2(1) = 4.56, p = .025$), the presence of physical adaptations in the living room ($\chi^2(1) = 14.62, p = .000$), the opportunity to follow ASD-specific training ($\chi^2(1) = 20.53, p = .000$), parental involvement ratings ($F(1,193) = 8.47, p = .004$), etc.

To summarize, the evaluation of the program input and process in Flemish schools [Chapter 1] and services for persons with a disability [Chapter 2] have demonstrated to what extent and in which areas organizations claiming to have an ASD-specific approach differ from other organizations. These points of difference largely correspond with the areas of evidence-based practice for persons with ASD, which are extensively described in the literature (e.g., Howlin, 1998; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999; Iovannone, Dunlap, Huber, & Kincaid, 2003; National Research Council, 2001). Further, the analyses revealed that the presence

of these areas of effective practice was associated with a higher number of persons with ASD registered in the organization. Mesibov (1999) reported on the characteristics of organizations serving a large number of persons with ASD. On the one hand, he asserted 1) that the best specific organization model (ASD-specific vs. non-specific) depends on the person with ASD's unique needs, and 2) that the quality of support or instruction is far more important to the individual with ASD than the organization model that incorporates that support or instruction. On the other hand, he stated that organizations without ASD-specific approach may not be tailored to the specific support needs of individuals with ASD. Part of the reason for that is that staff supporting persons with multiple disabilities might not have the background and extensive training that is crucial for supporting persons with ASD. The most important factor in the success of support for persons with ASD is neither the organization model, nor the diagnosis of other persons registered in the organization. Instead, it is the knowledge of the staff, their understanding of ASD, and their skills in supporting individuals with ASD (Mesibov, 1999; Peeters, 2000). According to Mesibov (1999) staff with expertise in ASD is more frequently found in organizations serving a large number of persons with ASD.

Our results not only substantiated the latter assertion of Mesibov, but also found a significant relationship between the number of persons with ASD registered in the organization and other areas of evidence-based practice specific for ASD. However, we acknowledge that these results per se provide no indication for the eventual short- or long-term outcome of support delivered to the individual with ASD. Therefore, the support experiences of parents of children with ASD and adults with ASD were examined in the second part of this dissertation.

Support needs and experiences of persons with ASD

Next to an evaluation of the quality of support by means of structural and process measures, information on the short-term outcomes (i.e. service users' satisfaction with the process and output) is considered to be of critical importance. The views of these most important stakeholders can directly be used to inform policy makers and professionals in the development, adaptation, and enhancement

of educational and service delivery systems for persons with ASD (Bromley, Hare, Davison, & Emerson, 2004; Sperry, Whaley, Shaw, & Brame, 1999). In Chapters 3 and 4, we investigated the short-term outcomes of formal support in respectively parents of children with ASD and adults with ASD. It was found that both groups were not univocally positive about the support received by the formal support network. Significant problems were found with respect to the diagnostic process, the availability of information on ASD, and the quality of the support received. The findings both confirmed existing literature in the field of ASD, and provided additional insights.

Firstly, the diagnostic process proved to encounter many difficulties. In comparison with many other disabilities, the diagnosis of ASD is often more problematic from the outset (Brogan & Knussen, 2003). Specific characteristics of ASD (e.g., the development of social and communication skills in a qualitatively abnormal fashion) do not always lead to concerns by parents and are often not recognized until the child starts in a preschool where the staff may be alerted to a social impairment in interaction with peers or adults, a lack of flexible play, or inability to cope with unstructured situations (Charman & Baird, 2002). The majority of the children, both in Flanders [see Chapter 3] and in other countries (Howlin & Asgarian, 1999; Howlin & Moore, 1997; Mandell, Listerud, Levy, & Pinto-Martin, 2002), do not receive a diagnosis until the average age of 5 or 6 years and after a delay of 2 to 4 years since the parents' first suspicions of a problem. With regard to the adults [Chapter 4], the major part of them did not obtain the diagnosis of ASD before the age of 12. This late age of diagnosis in adults with ASD is most probably due to the fact that the understanding of ASD and its recognition has expanded only recently. Besides, there is currently more media and public interest in the topic, with publication of personal stories and descriptions of children's behaviour, which probably guides parents to instigate referral to diagnostic centres (Charman & Baird, 2002). However, in spite of the growing amount of attention currently being paid to ASD, the average age of diagnosis is still high. In view of the increasing empirical evidence that appropriately targeted early intervention improves outcome in children with ASD (Corsello, 2005; Howlin, 1997; Lord, 1995), it is indispensable to make systematic efforts to identify ASD at younger ages.

In addition to the late age of diagnosis, the information on ASD provided by professionals during the disclosure interview and thereafter, appeared to be a cause of discontent, both in parents of children with ASD and adults with ASD. Brogan and Knussen (2003) and Whitaker (2002) brought similar problems of accessibility of ASD-specific information in the UK under attention and stressed the overwhelming importance of qualitative information during and after the disclosure of a diagnosis. Recent guidelines for good practice in the disclosure of a disability emphasize the importance of the manner of the professional during the disclosure interview and the way in which information can be given most effectively (Brogan & Knussen, 2003; NIASA, 2003).

Finally, the quality of support as perceived by parents of children with ASD and adults with ASD was investigated. The results of Chapter 3 strengthened previous studies examining parents' perceptions of the support received for their child with ASD (e.g., Bromley et al., 2004; Sperry et al., 1999). Parents whose child attended a specialist organization expressed higher levels of satisfaction than parents of children attending a mainstream organization. Since this finding merely provided information on the organization model parents prefer (specific vs. non-specific) (i.e. between-groups approach), further insight was gained into the factors that contributed to higher or lower levels of parental satisfaction (i.e. within-groups approach). The key factors of qualitative support for children with ASD, as identified by the parents, largely corresponded with the factors that were significantly associated with organizations claiming to have an ASD-specific approach (see Chapter 1 and 2), such as individualization, parental involvement, ASD-specific knowledge of the staff, etc. Even though these factors were far less common in mainstream and categorical organizations without an ASD-specific approach, the recognition of these predictors of parental satisfaction should enable unspecialized organizations to redirect their input resources and process at influencing these predictors with the clear anticipation of improving the quality of support for their students or service users with ASD.

In addition to the key elements of effective support that were identified by parents of children with ASD, adults with high-functioning ASD [Chapter 4] expressed the need for support that is characterized by self-determination and self-realization, comprehensiveness, respect, equality, flexibility, and partnership.

Whereas parents of children with ASD emphasized the specificity of the support needed for their child with ASD, adults with high-functioning ASD also stressed the importance of support that is consistent with the quality of life discourse (which stresses the implementation of the related concepts of self-determination, personal growth, individualized support, social inclusion, etc.). Although it is obvious that the emphasis on specific interventions and therapy is more significant in children with ASD than in adults, it is remarkable that quality of life issues in children have received little attention, both in research and in practice (Wallander, Schmitt, & Koot, 2001). The growing body of publications on children's rights on the one hand (John, 2003) and on quality of life on the other hand, will probably bring issues of children's quality of life more and more under attention.

Finally, the second theme of the present dissertation also focused on the discrepancy between received and needed support as an indicator of the quality of support received. In Chapter 4, we examined how well formal and informal support were tailored to the specific support needs of adults with high functioning ASD. It was found that support needs were most generally met for the areas requiring practical support. In contrast, needs in the areas of interpersonal relations and psychosocial well-being were largely unmet. This suggests either that these areas suffered from a relative neglect of professional supporters or that professionals were ineffective in meeting these support needs. In line with this, Tantam (2000) reported earlier on the general lack of psychotherapy or counselling which can alleviate the intra- and interpersonal difficulties many persons with ASD contend with. Further, our results provided empirical evidence for the assumption that, with regard to the focus of the support system, there is a hierarchy in the core quality of life dimensions. The primary focus of the support system is assumed to be the physical and material well-being of the person with a disability, whereas emotional well-being, social inclusion and interpersonal relationships are of less relevance for policymakers (Schalock & Verdugo, 2002). Nevertheless, the latter dimensions are often valued highest by individuals with a disability (Schalock, 2000).

The predictive value of formal and informal support for the quality of life in adults with ASD

The final major aim of this dissertation was to identify predictors of better long-term outcome in persons with ASD. In Chapter 5 and 6, we investigated whether the severity of the disability and the amount of formal and informal support were associated with the outcome in adults with high functioning ASD and their spouses.

We found no evidence that disability characteristics (i.e. intellectual ability and autism severity) contribute to the prediction of long-term outcomes in adults with ASD. This finding is partly consistent with earlier reports on long-term outcomes of adults with ASD. Howlin, Goode, Hutton, and Rutter (2004) found that, amongst individuals with IQ-scores above 70, variations in the level of intellectual ability were of little predictive value in terms of outcome. In contrast with our findings, Howlin and colleagues (Howlin et al., 2004) assumed that the fundamental deficits associated with ASD significantly impact the outcome and go beyond the effect of a high level of intelligence. While it is possible that our measure of autism severity (i.e. the Autism-spectrum Quotient) failed to tap ASD-specific deficits that specifically impact outcome in adult life, the low association between severity of the disability and long-term outcome may also be due to the buffering effects of other factors, such as social support, coping, appraisal of the stressor, etc. (Cohen & Hoberman, 1983; McCubbin & Patterson, 1983). Many studies have provided empirical evidence for the fact that the severity of the disability has less impact on outcome than other variables such as coping strategies and social support (e.g., Bristol, 1987; Pakenham, Samios, & Sofronoff, 2005; Reddon, McDonald, & Kysela, 1992). This finding was confirmed in Chapter 5 and 6 of the present dissertation. Support characteristics accounted for 27% - 89% of the variance over and above disability characteristics, suggesting that the social support is one of the most critical factors for successful long-term outcome in adults with ASD.

With respect to the outcomes in spouses of adult men with ASD, Chapter 6 revealed substantial parallels with the findings described above, with the exception

of two findings. Firstly, whereas autism severity was not correlated with outcome in adults with ASD, it was found that marital adaptation in spouses of men with ASD was inversely associated with the severity of autism of their husbands. However, this effect was buffered by the spousal support as perceived by the women. Secondly, whereas higher levels of (perceived) informal support were related with better outcome in adults with ASD, better individual adaptation in women was related with less support received from family, friends, and acquaintances. Longitudinal data are necessary to sort out the direction of the association between received support from family, friends, and acquaintances and psychosocial distress in women. It may be that women with higher levels of psychological distress (and consequently with higher support needs) elicit more informal support from family, friends, and acquaintances.

In addition to these findings concerning the predictive value of disability and support characteristics, two specific findings warrant further attention. Firstly, Chapter 5 and 6 largely provided evidence for the notion that perceived social support has a much stronger influence on outcome than the actual receipt of social support (Dunkel-Schetter & Bennett, 1990; Wethington & Kessler, 1986). Perceived social support proved to be a unique predictor of outcome in the samples of both the adults with ASD [Chapter 5 and 6] and the spouses of adults with ASD [Chapter 6]. Secondly, it was demonstrated that the role of formal support was less univocal. Whereas the discrepancy between received and needed formal support strongly contributed to the prediction of quality of life in (predominantly single) adults with ASD, no formal support variable was found to be associated with either individual or marital adaptation in men with ASD and their spouses. These divergent findings potentially resulted from differences in formal support needs and thus from the role that professionals fulfil as sources of support. Persons with ASD who are married and have children presumably have less formal support needs than individuals who do not have an intimate relationship. Moreover, an intimate, confiding relationship is described to be the most powerful source of social support (Cohen & Wills, 1985; Thoits, 1995) and thus presumably decreases the need for professional or other sources of social support.

THEORETICAL IMPLICATIONS

To our opinion, the present dissertation both complemented and elaborated existing theory and research on support and quality of life. Since Chapter 1 to 4 principally dealt with descriptive data on the quality of support and the support experiences of persons with ASD, these chapters particularly lead to clinical and policy implications. The discussion of the major theoretical implications of the present thesis principally results from Chapter 5 and 6, which examined the association between stressor severity and support characteristics on the one hand and long-term outcomes on the other hand.

According to the double ABCX-model, successful adaptation to a stressor is determined by the interaction of several components: the severity of the stressor, the family resources, the appraisal of the stressor, and the coping strategies employed. It is emphasized that, although the stress associated with the presence of a disability is an important consideration, the available resources and the coping strategies used are expected to be more related with the outcome of individuals (McCubbin & Patterson, 1983). Our empirical findings in Chapter 5 and 6 are to a large extent consistent with this theoretical model. Firstly, our results provided empirical evidence for the notion that the severity of a disability is not necessarily associated with worse long-term outcomes. The degree of autism-specific traits was neither related with the quality of life of adults with ASD [Chapter 5], nor with individual and marital adaptation in married men with ASD [Chapter 6]. Secondly, our findings provided compelling evidence for the notion that social support has a beneficial effect on outcome in adults with ASD. Although the significant effect of social support has continuously been confirmed in studies among a large variety of clinical groups (e.g., Feldman, Varghese, Ramsay, & Rajska, 2002; Florian & Dangoor, 1994; Holland & Holahan, 2003), its relevance for adults with ASD was less clear until now. The restricted communicative and social-interactive capabilities of individuals with ASD often entail more difficulties regarding the development or sustainment of peer relationships or supportive networks as compared to persons with other disabilities [Chapter 4]. Although the value of social support was at first sight thus less unambiguous in persons with a social

impairment, our results established conclusive evidence of social support being a significant predictor of long-term outcome in persons with ASD.

Furthermore, our findings strengthen the claims of many previous authors that it is important to distinguish between received social support (i.e. the actual transfer of advice, aid, and affect through interpersonal networks) and perceived social support (i.e. the perception that the social network is ready to provide support and aid if needed) (e.g., Cohen & Hoberman, 1983; Dunkel-Schetter & Bennett, 1990; Wethington & Kessler, 1986; White & Hastings, 2004). We found that perceived social support has a much stronger influence on outcome than the actual receipt of social support. Probably, the buffering qualities of social support are cognitively mediated, and thus the perception of the availability of support is a more sensitive indicator of its buffering effect than objective received support measures (Cohen & Hoberman, 1983). Although existing research on the significant role of social support rarely makes explicit whether a measure of received or perceived social support was used (White & Hastings, 2004), our results underscore the importance of a distinction between both constructs.

Finally, from a sociological point of view, the findings of the present dissertation supported the notion of the social model of disability, in which disability is defined as a social pathology (Oliver, 1996; Race, Boxall, & Carson, 2005). This approach emphasizes that the extent to which one is 'disabled' is not only the result of factors residing in the individual, but mainly of the interaction between the individual and the environment. Barnes and colleagues (Barnes, Mercer, & Shakespeare, 1999) stressed the significance of social and material conditions as key factors for the individual's experience of disability. Our results in Chapter 5 underline the importance of this good person-environment fit.

LIMITATIONS AND CRITICAL REFLECTIONS

Next to the limitations that were already discussed in each of the preceding chapters, we would like to deal with some general limitations that refer to the dissertation as a whole.

The first and most important limitation of the current dissertation concerns the heterogeneity of the study foci. The present dissertation has tapped a large variety of issues related to optimal support for persons with ASD throughout the whole lifespan, ranging from the presence of areas of effective practice in educational provisions to successful adaptation in spouses of adult men with ASD. Although the variety of study foci has resulted in a dissertation with miscellaneous results and a wide range of practical implications, the diversity has restrained us from integrating the study results into a concise summary addressing one core theoretical question. The heterogeneousness of studies has to be understood from the background of this dissertation. Whereas the descriptive studies in the first chapters [Chapter 1, 2 and 3] stemmed from a research project under the authority of the Flemish parent organization for autism [VVA], the last three studies [Chapter 4, 5 and 6] occurred on a PhD grant and aimed at investigating the relationship between quality of support and quality of life on a more fundamental level.

A second important limitation concerns the lack of longitudinal data on quality of support and quality of life in persons with ASD. Although the theoretical rationale behind our studies claims that social support affects the long-term outcome, the cross-sectional research design used in Chapter 5 and 6 does not permit to infer causality. Longitudinal data would be necessary to ascertain the causal relation between the variables under study. Besides, it would have been interesting to investigate all components of the Program Logic Model (Schalock & Bonham, 2003) within the same sample of persons with ASD over a long period of time. In the dissertation at hand, the components of Schalock and Bonham's (2003) model were examined in different studies, using different samples. Although our first four chapters were capable of tapping some important weaknesses in the current support and educational provisions for persons with ASD, the lack of longitudinal, intra-individual data hindered us from identifying specific support characteristics (input and process components) resulting in better long-term outcomes for persons with ASD.

Thirdly, the studies addressing the first major aim of this dissertation [Chapter 1 and 2] focused solely on the program input and process in educational and service provisions, without taking into account the intensity of the support

delivered and the specific support needs of the individuals appealing to the schools or services concerned. Next to the fact that it was our assignment (see above) to evaluate the quality of support for persons with ASD in Flanders within a short period of time, three methodological considerations persuaded us to employ structural and process measures, rather than program output measures, in the two chapters at issue. Firstly, methodological objections are raised regarding the use of output measures in the assessment of quality of support. Since output is commonly affected by multiple factors (of which some are not under control of an organization), conclusions on the quality of support merely based on output measures may be invalid (Derose & Petitti, 2003). Secondly, the relative large amount of evidence-based literature on effective interventions for persons with ASD enabled us to specify some 'standards of support' by means of which input and process were evaluated. The final methodological consideration was a rather practical one. Structural and process measures are often preferred because of their relative ease of measurement. Both these dimensions are easily recognizable and observable. However, it is important to acknowledge that input and process evaluations provide only an indirect measure of quality of life and fail to gauge the experiences of the persons with a disability. Structural and process measures assume all clients to be the same and do not take into consideration the specific environmental factors that are important to individuals (Bellamy, Newton, LeBaron, and Horner, 1990). We are aware that Chapter 1 and 2 merely focused on input and process evaluation, which made these studies programme-centred rather than client-centred. Since we were not able to enquire for the specific support needs and experiences of the consumers in the organizations under study in the first chapters, we have tried to address this issue in Chapter 3 and 4. In these chapters, we took a client-centred approach and investigated the fit between received and needed support, from the perspective of parents of children with ASD and adults with ASD respectively.

Fourthly, for each of the studies described, the sample has been based on participants (e.g., organizations, parents, adults with ASD) who voluntarily took part in the research. It is important to be aware that, due to selection biases, the samples of the respective chapters may not be representative of the whole population. Therefore, the generalizability of the findings may be limited.

Furthermore, in Chapter 6, the sample size was rather small, raising the possibility that some results may be spurious.

Finally, the results of each of the chapters are based on self-report measures only. The findings may have been subject to single informant bias as well as single method bias, which possibly may have inflated the associations found in Chapter 5 and 6. Furthermore, relying merely on self-report data for the measurement of long-term outcomes may have limited the validity of the findings. Barry and Zissi (1997) questioned the sensitivity of quality of life measures in assessing outcomes affected by supportive interventions. On that subject, Schalock (2004) asserted that a methodological pluralism approach to quality of life assessment enables researchers to tap all dimensions of the quality of life concept, and allows one to incorporate multiple perspectives of the concept and to meet methodological objectives of triangulation and complementarity (i.e. the use of qualitative and quantitative methods to measure the overlapping, but distinct facets of the quality of life construct).

CLINICAL AND POLICY IMPLICATIONS

In spite of the above-mentioned limitations, the present dissertation provided in many respects valuable information on how formal and informal support networks may enhance the quality of their supportive actions and as a result, the quality of lives of persons with ASD.

The quality of support for persons with ASD

Several authors (e.g., Charman & Baird, 2002; Ruble et al., 2005) notified that the increasing prevalence of ASD has significant implications for the educational and service provisions for persons with ASD. Given the variation that is seen in the presentation of ASD over individual persons and the variation in the person's response to different interventions and milieus, we would like to emphasize that the results of the present dissertation are not aimed at designating one organization-model that is preferable above the others for all persons with

ASD. In contrast, we would like to use the information on the weaknesses in the current formal support systems for persons with ASD [Chapter 1 and 2] to set up lines of policy, aiming at enhancing the quality of support in all organizations. The following findings should lead to important policy implications.

Firstly, the age of diagnosis should be reduced drastically. We agree with Charman and Baird (2002) that primary healthcare practitioners which are often first consulted by the parents, such as general physicians, school psychologists, and nursery school staff, need to be made aware through training which early signs of possible ASD warrant further investigation and which services experienced in child development are appropriate to refer to. As for Flanders, the first steps in early identification of children with ASD have been undertaken by the centres for school psychologists which implemented a step-by-step plan designed for the early identification of ASD in pre-schoolers.

Secondly, services and schools that claim to adapt the support to the specific needs of persons with ASD frequently contend with a lack of resources regarding personnel, training, infrastructure, and materials [Chapter 1 and 2]. We presume that a linking between the amount of subsidies organizations receive and the intensity of support needs of each individual service user or student, would give room to the optimization of support for persons with high support needs.

Thirdly, the difficulties in terms of accessibility of organizations claiming to have an ASD-specific approach should be dealt with. Both the consumers [Chapter 3 and 4] and the organizations [Chapter 1 and 2] complained with the long waiting lists in services and schools having an ASD-specific approach. Furthermore, organizations with an ASD-specific approach are significantly associated with the number of persons with ASD registered in the organization. Action should be taken to decrease accessibility problems of organizations providing specialized support for persons with ASD. In addition to the financial measures described above, the introduction of ASD-specific training in the basic curriculum of future teachers and service staff may result in more knowledge about the disorder. This may in turn affect the responsiveness of both mainstream and categorical organizations to the specific support needs of persons with ASD, and as a result diminish the high number of persons with ASD in specialized settings.

Finally, not only professionals should be able to easily access information and training about ASD; also parents of children with ASD and adults with ASD should be provided with more information about the disorder. In consideration of this need for information, there should be a general opportunity for post-diagnostic counselling. These consultations should be the gateway to appropriate support from both the informal and the formal network and they should ensure that the child or adult with ASD accesses the necessary (educational and) service provisions as quickly and as smoothly as possible.

The significant role of social support

Given the unequivocal role that social support plays in the long-term outcomes of persons with ASD [Chapter 5 and 6] and considering the adverse influence of a discrepancy between received and needed support in (predominantly single) adults with ASD [Chapter 5], social support should be tailored precisely to the individual needs of persons with ASD. Addressing the unique priorities, preferences, and support needs of persons with ASD by means of a quality of life-directed approach, such as person-centred planning, enables individuals to realign both formal and informal resources to achieve desired outcomes (Butterworth, Steere, & Whitney-Thomas, 1997). Although the actual implementation of person-centred planning occurs only gradually in Flanders, this approach creates explicit opportunities to enlarge the supportive social network of the person with ASD and to systematically evaluate any discrepancies between the support received and needed.

In addition, with respect to the significant role of social support in couples with one spouse having ASD, we found that spousal support is significantly associated with marital adaptation in both men with ASD and their spouses [Chapter 6]. Although this finding is well-established in the general support and marital research literature (e.g., Pasch & Bradbury, 1998), in the context of couples with one spouse having ASD it may lead to an important clinical implication. Instead of focusing on the disability of the spouse with ASD and the problems associated with it, marital programmes should provide support training for both the partners. By means of support training, the spouses are taught how to respond

effectively to the individual or interpersonal difficulties of the partner and how to best convey their own difficulties so as to solicit effective support from their partner (Cutrona, 1996; Pasch & Bradbury, 1998). In this respect, Cordova (2001) asserted that, although it is appropriate and necessary to address conflict in marital programmes, focusing exclusively on conflict may limit the breadth and effectiveness of these programmes.

Persons with ASD as core informants

Although it was not a specific research aim of the current dissertation, the studies described in the last three chapters have illustrated the ability of adults with high functioning ASD to reflect on and to communicate personal thoughts and feelings about their individual situation. The following conditions may have contributed to what, in our opinion, was a successful effort to systematically investigate the opinions of adults with high functioning ASD. Firstly, a selection factor is applicable; all adults who participated in the studies had relatively high levels of verbal abilities. Secondly, an interviewer factor may have contributed. The interviews were conducted in a systematic and highly structured way. Thirdly, an instrument factor may be relevant. Although not all instruments were originally designed for persons with ASD, the selection of the questionnaires and interviews occurred to a large extent on the basis of the supposed receptive and expressive communication abilities of the participants with ASD.

DIRECTIONS FOR FUTURE RESEARCH

Since only few studies have been undertaken with the aim of investigating the quality of support and the quality of life of persons with ASD, several directions for future research can be formulated. In the following, some general suggestions are offered in addition to the specific recommendations that were discussed in each of the preceding chapters.

Firstly, there is no doubt that in every respect more in-depth research is indicated as to the impact of support characteristics on the quality of life in persons

with ASD. In correspondence with the second point raised in the limitations section of this general discussion, specific components of the Program Logic Model (Schalock & Bonham, 2003) have been tested separately throughout this dissertation. However, future research in the field should collect longitudinal – and thus intra-individual – data on every single component of the model. By testing hypotheses including the model as a whole, assertions could be substantiated on the causal effect of specific support interventions on long-term outcomes. However, in the explorative phase of examining quality of support and quality of life in persons with ASD, an uncomplicated, incomplete model was preferred to a comprehensive but complex model.

Secondly, future studies investigating the short-term outcomes of persons with ASD should incorporate more intra-individual (e.g., intellectual ability, autism severity, age) and environmental factors (e.g., family size, SES), which may influence satisfaction scores and support experiences. Although the qualitative results of Chapter 3 and 4 enabled us to make some preliminary statements about the importance of some intra-individual characteristics, these findings await replication and extension in research using quantitative measures.

Furthermore, in the present dissertation, the association between support characteristics and long-term outcomes was merely investigated in a sample of adults with high functioning ASD. Future research should investigate whether our results on the association between social support and long-term outcomes hold for other groups within the autism spectrum, such as children and persons with an intellectual disability. In consideration of the fact that these groups presumably will have more intense support needs as compared to adults with high functioning ASD, it is not clear whether the relation between disability and support characteristics on the one hand and long-term outcomes on the other hand is similar for all persons with ASD, irrespective of age and intellectual ability.

Although both qualitative and quantitative methods have been used in the present dissertation, the use of measurement methods different from self-reports would possibly have led to alternative conclusions. Borthwick-Duffy (1996) asserted that the methods of measurement selected, possibly lead to varied conclusions about the quality of life or the predictors of a good quality of life. Both

with respect to the quality of life measurement and the measurement of support and disability characteristics, future research that uses alternative measurement approaches should confirm the results found in the present dissertation.

Finally, in line with the Program Logic Model (Schalock & Bonham, 2003), it would be interesting to conduct participatory action research in which outcomes are not merely measured but also used to 'manage for results'. The Program Logic Model demonstrates - by means of the feedback loop from outcomes to process - the important role that feedback regarding output and outcomes plays in programmatic processes. Future research addressing the process of monitoring quality enhancement and actively involving the most important stakeholders in this process (i.e. persons with ASD themselves) would contribute to our collective understanding of how quality of life can be further conceptualized, what a life of quality looks like for persons with ASD, and how outcomes can be improved (Whitney-Thomas, 1997). Although similar research has recently been introduced in the field of intellectual disabilities (cf. Ask Me! Project) (Bonham et al., 2003), its implementation in the field of ASD presumably would result in valuable knowledge on relatively unique and specific predictors of the quality of life of persons with ASD.

What we know and continue to learn about the concept of quality of life and its application to persons with ASD should make a difference in the persons' lives as well as in the policies and practices that impact their lives. At its core, the quality of life concept can give us a sense of reference and guidance from the individual's perspective, an overarching principle to enhance people's well-being and a common language and systematic framework to guide our current and future endeavours (Schalock, 2004).

NEDERLANDSE SAMENVATTING

Recente publicaties verlenen steeds meer empirische evidentie voor een toename in de prevalentie van autismespectrumstoornissen (ASS). Tot op heden focusten onderzoekers zich in de eerste plaats op potentiële verklaringen voor deze bevinding (vb. Croen, Grether, Hoogstrate, & Selvin, 2002; Gernsbacher, Dawson, & Goldsmith, 2005; Wing & Potter, 2002). Er werd echter relatief weinig aandacht geschonken aan de implicaties van deze toename voor diensten die onderwijs en ondersteuning verlenen aan personen met ASS. Nochtans wordt verwacht dat deze verhoogde prevalentie belangrijke gevolgen heeft voor de toegankelijkheid en de kwaliteit van het onderwijs- en ondersteuningsaanbod (Ruble, Heflinger, Renfrew, & Saunders, 2005). Dit doctoraatsproefschrift heeft tot doel zowel de kwaliteit van ondersteuning voor personen met ASS te beschrijven [Hoofdstuk 1-4] als de predictieve waarde van formele en informele ondersteuning voor de kwaliteit van leven van deze groep te evalueren [Hoofdstuk 5-6]. Het proefschrift bestaat uit 3 delen, die telkens uit 2 hoofdstukken zijn opgebouwd.

In *Deel I* [Hoofdstuk 1 en 2] wordt de toegankelijkheid en de kwaliteit van onderwijs en ondersteuning geëvalueerd in 172 scholen voor Buitengewoon Onderwijs, 70 reguliere scholen en 352 voorzieningen waar personen met ASS een beroep op doen.

Eenzijds tonen de resultaten van beide studies aan dat een aantal factoren de toegang tot organisaties met een aangepast onderwijs- of ondersteuningsaanbod voor personen met ASS bemoeilijken, zoals de wachtlijsten, de toegangsvoorwaarden die sommige voorzieningen hanteren, de ondoorzichtigheid van het onderwijs- en ondersteuningslandschap in Vlaanderen, enz. Gezien de

evidentie dat gerichte en aangepaste interventie ten aanzien van de persoon met ASS resulteert in een verbeterde uitkomst, is het echter van primordiaal belang dat het toegang krijgen tot autisme-specifieke ondersteuning snel en makkelijk verloopt (National Research Council, 2001). In de literatuur heerst er consensus over het feit dat personen met ASS specifieke onderwijs- en ondersteuningsbehoeften hebben, zowel op vlak van inhoud en vorm van het curriculum / de interventie, als op vlak van organisatie en structuur van de omgeving. Het is algemeen aanvaard dat deze ondersteuningsbehoeften in belangrijke mate verschillen van de noden van personen met een verstandelijke beperking (Charman & Baird, 2002).

Anderzijds laten de resultaten van het eerste deel van het proefschrift zien dat de kwaliteit van onderwijs en ondersteuning voor personen met ASS in Vlaanderen vatbaar is voor verbetering. Minder dan de helft van de organisaties die personen met ASS ondersteunt, geeft aan dat er specifieke inspanningen worden geleverd om tegemoet te komen aan de specifieke ondersteuningsbehoeften van deze groep. Deze aanpassingen situeren zich voornamelijk op het vlak van de communicatie, de organisatie van de omgeving, het curriculum, de samenwerking met de ouders en de autisme-specifieke kennis van het personeel. Deze domeinen stemmen grotendeels overeen met wat in de literatuur wordt beschreven als ‘good practice’ in de ondersteuning van personen met ASS (Howlin, 1998; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999; Iovannone, Dunlap, Huber, & Kincaid, 2003; National Research Council, 2001). Hoewel de resultaten van het eerste deel van het proefschrift een beeld schetsen van de wijze waarop in Vlaanderen vorm wordt gegeven aan onderwijs en ondersteuning voor personen met ASS, is het niet mogelijk aan de hand van deze bevindingen concrete uitspraken te formuleren over de korte- en lange termijn uitkomst van deze ondersteuning bij personen met ASS zelf. Dit vormde het onderwerp van het tweede deel van dit proefschrift.

In *Deel II* wordt ingegaan op de ervaringen met formele steun van 244 ouders van kinderen met ASS [Hoofdstuk 3] en van 58 volwassenen met ASS [Hoofdstuk 4]. Beide studies wijzen op een aantal belangrijke tekortkomingen met betrekking tot de diagnosestelling, de toegankelijkheid van autisme-specifieke informatie en de kwaliteit van onderwijs en ondersteuning. Deze bevindingen liggen in de lijn van andere internationale studies (vb. Brogan & Knussen, 2003;

Bromley, Hare, Davison, & Emerson, 2004; Howlin & Moore, 1997; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Sperry, Whaley, Shaw, & Brame, 1999).

Ten eerste, op vlak van het diagnostisch proces worden verschillende moeilijkheden gemeld. In vergelijking met andere beperkingen, verloopt de diagnose van ASS vaak moeizamer. De specifieke kenmerken van ASS (zoals de kwalitatieve beperkingen op vlak van sociale en communicatieve vaardigheden) leiden niet altijd tot ouderlijke bezorgdheid en worden vaak niet herkend tot het kind in de kleuterschool een aantal moeilijkheden ondervindt die door de omgeving als eerste alarmsignalen gepercipieerd worden (vb. in het contact met leeftijdsgenoten of volwassenen). Bovendien wordt in Vlaanderen de diagnose gemiddeld pas gesteld 2,12 jaar na de eerste professionele consultatie door de ouders, wat de gemiddelde diagnoseleeftijd van lagere schoolkinderen op 5,78 jaar brengt. Hoewel in de afgelopen decennia heel wat aandacht besteed werd aan het herkennen van de stoornis bij zeer jonge kinderen, is de huidige diagnoseleeftijd nog steeds te hoog. Gezien het prognostisch belang van specifieke interventies bij zeer jonge kinderen (Corsello, 2005; Howlin, 1997; Lord, 1995), zouden systematische inspanningen moeten worden geleverd om de diagnoseleeftijd naar beneden te halen.

Een tweede bron van ontevredenheid bij de gebruikers betreft de informatievertrekking over ASS, zowel tijdens het adviesgesprek als daarna. De gekregen informatie is vaak te beperkt, is weinig toegespitst op de specifieke, unieke en individuele moeilijkheden van de persoon met ASS, en ze refereert te weinig naar geschikte instanties voor onderwijs en ondersteuning. Zoals eerder gesuggereerd door Brogan en Knussen (2003) zou de mogelijkheid tot post-diagnostische consultaties moeten worden geboden waarin antwoord wordt gegeven op de praktische en inhoudelijke vragen van alle belanghebbenden.

Tenslotte werden individualisatie, autisme-specifieke kennis van ondersteuners, ouderlijke betrokkenheid, en continuïteit van het personeel benoemd door ouders van kinderen met ASS als sleutelfactoren voor kwaliteitsvolle ondersteuning van hun kind met ASS. De volwassenen met ASS [Hoofdstuk 4] voegen hier een aantal factoren aan toe die zich meer situeren

binnen het ‘quality of life’ discours: het belang van zelfbepaling, zelfrealisatie, respect, gelijkheid, flexibiliteit, enz.

Deel III [Hoofdstuk 5 en 6] tracht een antwoord te bieden op de vraag naar de predictieve waarde van ondersteuning voor levenskwaliteit van personen met ASS. Voorgaand onderzoek naar lange termijn uitkomst van volwassenen met ASS spitste zich in de eerste plaats toe op het belang van de ernst van de handicap (vb. Howlin, Goode, Hutton, & Rutter, 2004), en besteedde weinig aandacht aan het belang van formele en informele ondersteuning. Het laatste deel van dit proefschrift levert echter duidelijke empirische evidentie voor het feit dat sociale steun een significante en unieke voorspeller is van levenskwaliteit bij volwassenen met ASS, alsook bij partners van personen met ASS. Met betrekking tot informele steun, blijkt vooral de ervaren sociale steun in belangrijke mate geassocieerd te zijn met het welbevinden. Op vlak van formele steun heeft de hoeveelheid gekregen steun geen significant belang, maar wel de effectiviteit van de steun (i.e. de discrepantie tussen de gekregen en nodige steun). Deze bevinding geldt echter enkel voor de (hoofdzakelijk alleenstaande) volwassenen uit Hoofdstuk 5.

Dit doctoraatsproefschrift leidt tot een aantal belangrijke praktische implicaties en beleidsaanbevelingen. Terwijl Deel I en II in hoofdzaak tot aanbevelingen leiden met betrekking tot het optimaliseren van de formele ondersteuning voor personen met een ASS, zou naar aanleiding van Deel III meer aandacht geschonken moeten worden aan de implementatie van specifieke ondersteuningsmodaliteiten voor volwassenen met ASS, zoals Persoonlijke Toekomstplanning en interventies die zich richten op het verwerven van ondersteuningsvaardigheden.

Gezien het beperkt aantal studies dat tot op heden werd uitgevoerd met betrekking tot levenskwaliteit en kwaliteit van ondersteuning voor personen met ASS, strekt verder onderzoek in dit domein tot aanbeveling. In het proefschrift worden aanbevelingen geformuleerd aangaande het gebruik van longitudinale data, het gebruik van alternatieve onderzoeksmethoden, het incorporeren van meer intra-individuele en omgevingsfactoren, en het opzetten van participatorisch actie-onderzoek.

De afgelopen drie decennia heeft het concept levenskwaliteit steeds meer aan belang gewonnen, zowel in wetenschappelijk onderzoek (over verschillende disciplines heen), als in de praktijk. Het is belangrijk dat het ‘quality of life’ discours in de toekomst een belangrijke plaats op de onderzoeks- en praktijkagenda blijft behouden. Immers, het concept biedt ons een fundamentele leidraad om het perspectief van het individu te kiezen; het is een overkoepelend principe om het individueel welzijn van mensen te verbeteren; en het fungeert als een gemeenschappelijk referentiekader voor onze huidige en toekomstige inspanningen voor en met personen met een beperking (Schalock, 2004).

REFERENCES

- Ainscow, M. (1997). Towards inclusive schooling. *British Journal of Special Education*, 24, 3-6.
- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders (4th Ed., Text Revision)*. Washington, DC: American Psychiatric Association.
- Arrindell, W. A., & Ettema, J. H. M. (1986). *SCL-90. Handleiding bij een multidimensionele psychopathologie-indicator*. [Manual for a multidimensional indicator of psychopathology]. Lisse: Swets & Zeitlinger.
- Bailey, A. J., Palferman, S., Heavey, L., & Le Couteur, A. (1998). Autism: The phenotype in relatives. *Journal of Autism and Developmental Disorders*, 28, 369-392.
- Bailey, A. J., Phillips, W., & Rutter, M. (1996). Autism: Integrating clinical, genetic, neuropsychological, and neurobiological perspectives. *Journal of Child Psychology and Psychiatry*, 37, 89-126.
- Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., & Drew, A. (2000). A screening instrument for autism at 18 months of age: A six year follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 39, 694-702.

- Banerji, M., & Dailey, R. (1995). A study of the effects of an inclusion model on students with specific learning disabilities. *Journal of Learning Disabilities, 28*, 511-522.
- Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability. A sociological introduction*. Cambridge: Polity Press.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31*, 5-17.
- Barrera, M. J. (1981). Social support in the adjustment of pregnant adolescents: Assessment issues. In B. H. Gottlieb (Ed.), *Social networks and social support* (pp. 69-96). Beverly Hills CA: Sage.
- Barrera, M. J., Sandler, I. N., & Ramsey, T. B. (1981). Preliminary development of a scale of social support: Studies on college students. *American Journal of Community Psychology, 9*, 435-447.
- Barry, M. M., & Zissi, A. (1997). Quality of life as an outcome measure in evaluating mental health services: A review of empirical evidence. *Social Psychiatry and Psychiatric Epidemiology, 32*, 38-47.
- Beadle-Brown, J., Murphy, G., & Wing, L. (2005). Long-term outcome for people with severe intellectual disabilities: Impact of social impairment. *American Journal on Mental Retardation, 110*, 1-12.
- Bellamy, G. T., Newton, J. S., LeBaron, N. M., & Horner, R. H. (1990). Quality of life and lifestyle outcomes: A challenge for residential services. In R. L. Schalock (Ed.), *Quality of life: Perspectives and issues* (pp. 127-137). Washington, DC: American Association on Mental Retardation.

- Bernheimer, L., Gallimore, R., & Weisner, T. (1990). Ecocultural theory as a context for the individual family service plan. *Journal of Early Intervention, 14*, 219-233.
- Bonham, G. S., Basehart, S., Schalock, R. L., Marchand, C. B., Kirchner, N., & Rumenap, J. M. (2003). Consumer based quality of life assessment: The Maryland ask me! project. *Mental Retardation, 42*, 338-355.
- Borthwick-Duffy, S. A. (1996). Evaluation and measurement of quality of life: Special considerations for persons with mental retardation. In R. L. Schalock (Ed.), *Quality of Life. Volume 1. Conceptualization and Measurement* (pp. 105–119). Washington, DC: American Association on Mental Retardation.
- Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46*, 722-730.
- Boyd, R. D., & Corley, M. J. (2001). Outcome survey of early intensive behavioral intervention for young children with autism in a community setting. *Autism, 5*, 430-441.
- Brewin, C. (1992). Measuring individual needs for care and service. In G. Thornicroft, C. Brewin, & J. Wing (Eds.), *Measuring mental health needs* (pp. 220-236). London: Gaskell/Royal College of Psychiatrists.
- Bristol, M. M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G. Mesibov (Eds.), *The effects of autism on the family* (pp. 289-310). New York: Plenum.
- Bristol, M. M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the double ABCX model. *Journal of Autism and Developmental Disorders, 17*, 469-486.

- Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology, 24*, 441-451.
- Brogan, C., & Knussen, C. (2003). The disclosure of a diagnosis of an autism spectrum disorder. *Autism, 7*, 31-46.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism, 8*, 409-423 .
- Brook, R. H., McGlynn, E. A., & Shekelle, P. G. (2002). Defining and measuring quality of care: A perspective from US researchers. *International Journal for Quality in Health Care, 12*, 281-295.
- Brucker, P. (1994). The advantages of inclusion for students with learning disabilities. *Journal of Learning Disabilities, 27*, 581-582.
- Bundy, M. B. (1996). The interrelation of stress, appraisal, coping and adjustment in parents of children with autism. *Dissertation Abstracts International, 56*, 7090.
- Butterworth, J., Steere, D. E., & Whitney-Thomas, J. (1997). Using person-centered planning to address personal quality of life. In R. L. Schalock (Ed.), *Quality of Life. Volume II. Application to persons with disabilities* (pp. 5-23). Washington, DC: American Association on Mental Retardation.
- Carlberg, C., & Kavale, K. (1980). The efficacy of special versus regular class placement for exceptional children: A meta-analysis. *Journal of Special Education, 14*, 295-309.
- Chakrabarti, S., & Fombonne, E. (2001). Pervasive developmental disorders in preschool children. *Journal of the American Medical Association, 285*, 3093-3099.

- Charman, T., & Baird, C. (2002). Practitioner review: Diagnosis of autistic spectrum disorder in 2-and 3-year-old children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *43*, 289-305.
- Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences*. Mahwah: Lawrence Erlbaum Associates.
- Cohen, S., & Hoberman, H. (1983). Positive events and social supports as buffers of life change stress. *Journal of Applied Social Psychology*, *13*, 99-125.
- Cohen, S., & McKay, G. (1984). Social support, stress, and the buffering hypothesis: A theoretical analysis. In A. Baum, J. E. Singer, & S. E Taylor (Eds.), *Handbook of psychology and health, Volume 4* (pp. 253-267). Hillsdale, NJ: Erlbaum.
- Cohen, S., & Wills, T. A. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin*, *98*, 310-357.
- Cohen, S., Mermelstein, R., Kamarck, T., & Hoberman, H.M. (1985). Measuring the functional components of social support. In I.R. Samson & B.R. Sarason (Eds.), *Social support: Theory, research and application* (pp. 73-94). The Hague: Martinus-Nijhoff.
- Cordova, J. V. (2001). Broadening the scope of couples research: Pragmatics and prevention. In A. Booth, A. C. Crouter, & M. Clements (Eds.), *Couples in conflict* (pp. 105-114). Mahwah, NJ: Lawrence Erlbaum Associates.
- Corsello, C. M. (2005). Early intervention in autism. *Infants and Young Children*, *18*, 74-85.
- Coyne, J. C., & Downey, G. (1991). Social factors and psychopathology: Stress, social support, and coping processes. *Annual Review of Psychology*, *42*, 401-425.

- Croen, L. A., Grether, J. K., Hoogstrate, J., & Selvin, S. (2002). The changing prevalence of autism in California. *Journal of Autism and Developmental Disorders*, *32*, 207-215.
- Cummins, R. A. (1996). The domains of quality of life: An attempt to order the chaos. *Social Indicators Research*, *38*, 303-328.
- Cummins, R. A. (2000). Objective and subjective quality of life: An interactive model. *Social Indicators Research*, *52*, 55-72.
- Cummins, R. A. (2001). Living with support in the community: Predictors of satisfaction with life. *Mental Retardation and Developmental Disabilities Research Reviews*, *7*, 99-104.
- Cutrona, C. E., & Russell, D. (1987). The provisions of social relationships and adaptation to stress. In W. H. Jones & D. Perlman (Eds.), *Advances in Personal Relationships, Volume I* (pp. 37-67). Greenwich: JAI Press.
- Cutrona, C.E. (1996). *Social support in couples: marriage as a resource in times of stress*. Thousand Oaks CA: Sage.
- Dawson, G., & Watling, R. (2000). Interventions to facilitate auditory, visual, and motor integration in autism: A review of evidence. *Journal of Autism and Developmental Disorders*, *30*, 415-421.
- Dawson, G., & Osterling, J. (1997). Early intervention in autism: Effectiveness and common elements of current approaches. In M. J. Guralnick (Ed.), *The effectiveness of early intervention: Second generation research* (pp. 307-326). Baltimore: Brookes.
- De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child and Adolescent Psychiatry*, *7*, 131-136.
- Dennis, R. E., Williams, W., Giangreco, M. F., & Cloninger, C. L. (1993). Quality of life as context for planning and evaluation of services for people with disabilities. *Exceptional Children*, *59*, 499-512.

- Derogatis, L. R. (1977). *SCL-90: Administration, scoring and procedures manual-I for the R(evised) Version*. Baltimore: Johns Hopkins University School of Medicine, Clinical Psychometrics Research Unit.
- Derose, S. F., & Petitti, D. B. (2003). Measuring quality of care and performance from a population health care perspective. *Annual Review of Public Health, 24*, 363-384
- Donabedian, A. (1982). *Explorations in quality assessment and monitoring. Volume 2: The criteria and standards of quality*. Ann Arbor, MI: Health Administration Press.
- Dunkel-Schetter, C., & Bennet, T. L. (1990). Differentiating the cognitive and behavioural aspects of social support. In G. Sarason, B. R. Sarason, & G. R. Pierce (Eds.), *Social Support: An international view* (pp.267-296). New York: John Wiley & Sons.
- Dunlap, G. (1999). Consensus, engagement, and family involvement for young children with autism. *The Journal of the Association of Persons with Severe Handicaps, 24*, 222-225.
- Dunst, C. J., & Trivette, C. M. (1986). Looking beyond the parent-child dyad for the determinants of maternal styles of interaction. *Infant Mental Health Journal, 7*, 69-80.
- Dunst, C. J., & Trivette, C. M. (1990). Assessment of social support in early intervention programs. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of Early Childhood Intervention* (pp. 326-349). New York: Cambridge University Press.
- Dunst, C. J., Trivette, C. M., Hamby, D., & Pollock, B. (1990). Family systems correlates of the behavior of young children with handicaps. *Journal of Early Intervention, 14*, 204-218.
- Duvdevany, I., & Abboud, S. (2003). Stress, social support and well-being of Arab mothers of children with intellectual disability who are served by welfare

services in northern Israel. *Journal of Intellectual Disabilities Research*, 47, 264-72.

Edgerton, R. B. (1996). A longitudinal-ethnographic research perspective on quality of life. In R. Schalock (Ed.), *Quality of Life, Volume I. Conceptualization and Measurement* (pp. 83-90). Washington, DC: American Association on Mental Retardation.

Endler, N. S. (1997). Stress, anxiety and coping: The multidimensional interaction model. *Canadian Psychology*, 38, 136-153.

Engström, I., Ekström, L., & Emilsson, B. (2003). Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. *Autism*, 7, 99-110.

Falgaard Nielsen, L., Middelboe, T., Werdelin, G., Petersen, L., Mackeprang, T., Lykke Mortensen, E., Ramian, K., & Lindhardt, A. (1999). Need assessment in long-term psychiatric patients: Inter-rater reliability and test-retest reliability of the Danish version of the Camberwell Assessment of Need. *Nordic Journal of Psychiatry*, 53, 371-376.

Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, 41, 126-135.

Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, 16, 51-74.

Felce, D., & Perry, J. (2005). Factors associated with outcome in community group homes. *American Journal on Mental Retardation*, 110, 121-35.

Feldman, M. A., Varghese, J., Ramsay, J., & Rajska, D. (2002). Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 314-323.

- Florian, V., & Dangoor, N. (1994). Personal and family adaptation of women with severe physical disabilities: A further validation of the Double ABCX Model. *Journal of Marriage and the Family*, *56*, 735-746.
- Florian, V., & Krulik, T. (1991). Loneliness and social support of mothers in chronically ill children. *Social Science and Medicine*, *32*, 1291-1296.
- Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, *46*, 359-371.
- Folkman, S., & Lazarus, R. S. (1988). Coping as a mediator of emotion. *Journal of Personality and Social Psychology*, *54*, 466-475.
- Folstein, S.E., & Rosen-Sheidley, B. (2001). Genetics of autism: Complex aetiology for a heterogeneous disorder. *Nature Reviews Genetics*, *2*, 943-955
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, *33*, 365-382.
- Fombonne, E., Bolton, P., Prior, J., Jordan, H., & Rutter, M. (1997). A family study of autism: Cognitive patterns and levels in parents and siblings. *Journal of Child Psychology and Psychiatry*, *38*, 667-684.
- Freeman, A., Malone, J., & Hunt, G. E. (2004). A statewide survey of high-support services for people with chronic mental illness: assessment of needs for care, level of functioning and satisfaction. *Australian and New Zealand Journal of Psychiatry*, *38*, 811-818.
- Fuchs, D., & Fuchs, L. (1995). Sometimes separate is better. *Educational Leadership*, *52*, 22-26.
- Gabriels, R., Hill, D., Pierce, R., Rogers, S., & Wehner, B. (2001). Predictors of treatment outcome in young children with autism: A retrospective study. *Autism*, *5*, 407-429.

- Gernsbacher, M. A., Dawson, M., & Goldsmith, H. H. (2005). Three reasons not to believe in an autism epidemic. *Current Directions in Psychological Science, 14*, 55-58.
- Greenberg, J. S., Seltzer, M. M., Wyngaarden-Krauss, M., & Kim, H. (1997). The differential effects of social support on the psychological well-being of aging mothers of adults with mental illness or mental retardation. *Family Relations, 46*, 383-394.
- Gregory, N., Robertson, J., Kessissoglou, S., Emerson, E., & Hatton, C. (2001). Factors associated with expressed satisfaction among people with intellectual disability receiving residential supports. *Journal of Intellectual Disability Research, 45*, 279-291.
- Gresham, F. M., Beebe-Frankenberger, M. E., & MacMillan, A. (1999). Selective review of treatments for children with autism: Description and methodological considerations. *School Psychology Review, 28*, 559-575.
- Gresham, F., & MacMillan, D. (1998). Early intervention project: Can its claims be substantiated and its effect replicated? *Journal of Autism and Developmental Disorders, 28*, 447-456.
- Hakes, J. E. (2001). Can measuring results produce results: One manager's views. *Evaluation and Program Planning, 24*, 319-327.
- Han, H. R. (2003). Korean mothers' psychosocial adjustment to their children's cancer. *Journal of Advanced Nursing, 44*, 499-506.
- Hancock, T. B., & Kaiser, A. P. (2002). The effects of trainer-implemented enhanced milieu teaching on the social communication of children with autism. *Topics in Early Childhood Special Education, 22*, 39-54.
- Hansson, L., Bjorkman, T., & Svensson, B. (1995). The assessment of needs in psychiatric patients - Interrater reliability of the Swedish version of the Camberwell Assessment of Needs Instrument and results from a cross-sectional study. *Acta Psychiatrica Scandinavica, 92*, 285-293.

- Hansson, L., Sandlund, M., Bengtsson-Tops, A., Bjarnasson, O., Karlsson, H., Mackeprang, T., Merinder, L., Nilsson, L., Sorgaard, K., Vinding, H., & Middelboe, T. (2003). The relationship of needs and quality of life in persons with schizophrenia living in the community. A Nordic multi-centre study. *Nordic Journal of Psychiatry*, *57*, 5-11.
- Harrower, J. (1999). Educational inclusion of children with severe disabilities. *Journal of Positive Behavior Interventions*, *1*, 215-230.
- Harrower, J., & Dunlap, G. (2001). Including children with autism in general education classrooms. *Behavior Modification*, *25*, 762-784.
- Harvey, G. (1996). Quality in health care: Traditions, influences and future directions. *International Journal for Quality in Health Care*, *8*, 341-350.
- Hastings, R. P., & Brown, T. (2002). Behaviour problems of autistic children, parental self-efficacy and mental health. *American Journal on Mental Retardation*, *107*, 222-232.
- Hastings, R., Thomas, H., & Delwiche, N. (2002). Grandparent support for families of children with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, *15*, 97-104.
- Heal, L. W., Borthwick-Duffy, S. A., & Saunders, R. R. (1996). Assessment of quality of life. In J. W. Jacobson & J. A. Mulick (Eds.), *Manual of diagnosis and professional practice in mental retardation* (pp. 199-209). Washington, DC: American Psychological Association.
- Henderson, D., & Vandenberg, B. (1992). Factors influencing adjustment in the families of autistic children. *Psychological reports*, *71*, 167-171.
- Herman, S. E., & Thompson, L. (1995). Families perception of their resources for caring for children with developmental disabilities. *Mental retardation*, *33*, 73-83.

- Holland, K. D., & Holahan, C.K. (2003). The relation of social support and coping to positive adaptation to breast cancer. *Psychology and Health, 18*, 15-29.
- Hollingshead, A. B. (1975). *Four factor index of social status*. Unpublished manuscript, Yale University.
- Honig, A. S., & Winger, C. J. (1997). A professional support program for families of handicapped preschoolers: decrease in maternal stress. *The Journal of Primary Prevention, 17*, 285-296.
- Howlin, P. (1997). Prognosis in autism: Do specialist treatments affect long-term outcome? *European Child & Adolescent Psychiatry, 6*, 55-72.
- Howlin, P. (1998). Practitioner review: psychological and educational treatments for autism. *Journal of Child Psychology and Psychiatry, 39*, 307-322.
- Howlin, P. (2000). Outcome in adult life for more able individuals with autism and Asperger syndrome. *Autism, 4*, 63-83.
- Howlin, P., & Asgharian, A. (1999). The diagnosis of autism and Asperger syndrome: Findings from a survey of 770 families. *Developmental Medicine and Child Neurology, 41*, 834-839.
- Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in UK. *Autism, 1*, 135-162.
- Howlin, P., & Yates, P. (1999). The potential effectiveness of social skills groups for adults with autism: information update. *Autism, 3*, 299-307.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*, 212-229.
- Hughes, C., & Hwang, B. (1996). Attempts to conceptualize and measure quality of life. In R. L. Schalock (Ed.), *Quality of Life, Volume I: Conceptualization and Measurement* (pp. 51-61). Washington, DC: American Association on Mental Retardation.

- Hughes, C., Hwang, B., Kim, J. H., Eisenman, L. T., & Killian, D. J. (1995). Quality of life in applied research: A review and analysis of empirical measures. *American Journal on Mental Retardation, 99*, 623-641.
- Humberstone, V. (2002). The experiences of people with schizophrenia living in supported accommodation: a qualitative study using grounded theory methodology. *Australian and New Zealand Journal of Psychiatry, 36*, 367-372.
- Hurlbutt, K., & Chalmers, L. (2004). Employment of adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 19*, 215-22.
- Hurth, J., Shaw, E., Izeman, S., Whaley, K., & Rogers, S. J. (1999). Areas of agreement about effective practices among programs serving young children with autism spectrum disorders. *Infants and Young Children, 12*, 17-26.
- Iovannone, R., Dunlap, G., Huber, H., & Kincaid, D. (2003). Effective educational practices for students with autism spectrum disorder. *Focus on Autism and Developmental Disabilities, 18*, 150-165.
- John, M. (2003). *Children's Rights and Power: Charging up for a New Century*. London: Jessica Kingsley.
- Johnston, C., Hessel, D., Blasey, C., Eliez, S., Erba, H., Dyer-Friedman, J., Glaser, B., & Reiss, L. (2003). Factors associated with parenting stress in mothers of children with fragile X syndrome. *Journal of Developmental and Behavioral Pediatrics, 24*, 267-275.
- Karney, B. R., & Bradbury, T. N. (1995). The longitudinal course of marital quality and stability: A review of theory, method and research. *Psychological Bulletin, 118*, 3-34.

- Kasari, C., Freeman, S., Bauminger, N., & Alkin, M. (1999). Parental perspectives on inclusion: effects of autism and Down syndrome. *Journal of Autism and Developmental Disorders, 29*, 297-305.
- Kavale, K., & Forness, S. (2000). History, rhetoric and reality. Analysis of the inclusion debate. *Remedial and Special Education, 21*, 279-296.
- Kazak, A. E. (1986). Stress in families of children with myelomeningocele. *Developmental Medicine and Child Neurology, 28*, 220-228.
- Keith, K. D. (2001). International quality of life: Current conceptual, measurement, and implementation issues. *International Review of Research in Mental Retardation, 24*, 49-74.
- Keller, D., & Honig, A. S. (2004). Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry, 74*, 337-348.
- Kessler, R., & McLeod, J. (1985). Social support and psychological distress in community surveys. In S. Cohen & S. Syme (Eds). *Social support and health* (pp. 19-40). New York: Academic Press.
- Koegel, R. L. (2000). Interventions to facilitate communication in autism. *Journal of Autism and Developmental Disorders, 30*, 383-392.
- Koegel, R. L., Schreibman, L., Loos, L. M., Dirlichwilhelm, H., Dunlap, G., Robbins, F. R., & Plienis, A. J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders, 22*, 205-216.
- Konstantareas, M. M., Homatidis, S., & Plowright, C. M. S. (1992). Assessing resources and stress in parents of severely dysfunctional children through the Clarke modification of Holroyd Questionnaire on Resources and Stress. *Journal of Autism and Developmental Disorders, 22*, 217-234.
- Kurita, H., Koyama, T., & Osada, H. (2005). Autism-Spectrum Quotient-Japanese version and its short forms for screening normally intelligent persons with

- pervasive developmental disorders. *Psychiatry and Clinical Neurosciences*, 59, 490-496.
- Kwai-sang Yau, M., & Li-Tsang, C. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. *British Journal of Developmental Disabilities*, 88, 38-51.
- Lavee, Y., McCubbin, H. I., & Patterson, J. M. (1985). The Double ABCX Model of family stress and adaptation: An empirical test by analysis of structural equations with latent variables. *Journal of Marriage and the Family*, 47, 811-825.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lohr, K. N. (1990). *Medicare: A Strategy for Quality Assurance*. Washington, DC: National Academy Press.
- Lord, C. (1995). Follow-up of two-year-olds referred for possible autism. *Journal of Child Psychology and Psychiatry*, 36, 1365-1382.
- Lord, C., & Venter, A. (1992). Outcome and follow-up studies of high functioning autistic individuals. In E. Schopler & G. Mesibov (Eds), *High functioning individuals with autism*. New York: Plenum.
- Macintosh, K., & Dissanayake, C. (2004). Annotation: The similarities and differences between autistic disorder and Asperger's disorder: A review of the empirical evidence. *Journal of Child Psychology and Psychiatry*, 45, 421 – 434.
- Madden, N., & Slavin, R. (1983). Mainstreaming students with mild handicaps: Academic and social outcomes. *Review of Educational Research*, 53, 519-569.
- Mamlin, N. (1999). Despite best intentions: When inclusion fails. *The Journal of Special Education*, 33, 36-49.

- Mandell, D., Listerud, J., Levy, S., & Pinto-Martin, A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*, 1447-1453.
- Mansell, J., Ashman, B., Macdonald, S., & Beadle-Brown, J. (2002). Residential care in the community for adults with intellectual disabilities: needs, characteristics and services. *Journal of Intellectual Disability Research, 46*, 625-633.
- Mawhood, L., & Howlin, P. (1999). The outcome of a supported employment scheme for high functioning adults with autism or Asperger syndrome. *Autism, 3*, 229-253.
- Mawhood, L., Howlin, P., & Rutter, M. (2000). Autism and developmental receptive language disorder – a comparative follow-up in early adult life. I. Cognitive and language outcomes. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 41*, 547-559.
- McCrone, P., Leese, M., Thornicroft, G., Schene, A., Knudsen, H., Vázquez-Barquero, J., Lasalvia, A., Padfield, S., White, I., Griffiths, G., & the Epsilon Study Group (2000). Reliability of the Camberwell Assessment of Need – European Version – Epsilon Study 6. *The British Journal of Psychiatry, 177*, s34-s40.
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. In H.I. McCubbin, M. B. Sussman, & J. M. Patterson (Eds.), *Social stress and the family: Advances and development in family stress theory and research* (pp. 7-37). New York: Haworth.
- McCubbin, H., & Patterson, J. (1983). The family stress process: The double ABCX model of family adjustment and adaptation. *Marriage and Family Review, 6*, 7-37.

- McCubbin, M. A., & McCubbin, H. I. (1993). Family coping with health crisis: the resiliency model of family stress, adjustment and adaptation. In C. Danielson, B. Hamel-Bissell, & P. Winstead-Fry (Eds.), *Families, health and illness* (pp. 21-63). St. Louis: Mosby.
- McEachin, J., Smith, T., & Lovaas, O. (1993). Long-term outcome for children with autism who received early intervention behavioural treatment. *American Journal on Mental Retardation, 97*, 359-372.
- McGregor, E., & Campbell, E. (2001). The attitude of teachers in Scotland to the integration of children with autism into mainstream schools. *Autism, 5*, 189-207.
- McLeskey, J., Henry, D., & Hodges, D. (1999). Inclusion: What progress is being made across disability categories? *Teaching Exceptional Children, 31*, 60-64.
- Mesibov, G. (1997). Formal and informal measures on the effectiveness of the TEACCH programme. *Autism, 1*, 25-35.
- Mesibov, G. (1999). Are children with autism better off in an autism classroom or a multidisability classroom? *Journal of Autism and Developmental Disorders, 29*, 429.
- Mesibov, G., & Shea, V. (1996). Full inclusion and students with autism. *Journal of Autism and Developmental Disorders, 26*, 337-346.
- Middelboe, T., Mackeprang, T., Hansson, L., Werdelin, G., Karlsson, H., Bjarnason, O., Bengtsson-Tops, A., Dybbro, J., Nilsson, L., Sandlund, M., & Sörgaard, K. (2001). The Nordic study on schizophrenic patients living in the community. Subjective needs and perceived help. *European Psychiatry, 16*, 207-214.
- Moore, V., & Goodson, S. (2003). How well does early diagnosis of autism stand the test of time? *Autism, 7*, 47-63.

- Moore, V., & Goodson, S. (2003). How well does early diagnosis of autism stand the test of time? Follow-up study of children assessed for autism at age 2 and development of an early diagnostic service. *Autism, 7*, 47-63.
- Muhle, R., Trentacoste, S. V., & Rapin, I. (2004). The genetics of autism. *Pediatrics, 113*, E472-E486.
- Myles, B., Simpson, R., Ormsbee, C., & Erikson, C. (1993). Integrating preschool children with autism with their normally developing peers: Research findings and best practices recommendations. *Focus on Autistic Behavior, 8*, 1-20.
- National Research Council (2001). *Educating Children with Autism*. Washington, DC: National Academy Press.
- Nesbitt, S. (2000) An evaluation of multi-agency service provision for children with autistic spectrum disorders. *The British Journal of Developmental Disabilities, 46*, 43-50.
- NIASA (National Initiative for Autism: Screening and Assessment) (2003). *National Autism Plan for Children (NAPC)*. London, UK: National Autistic Society / NIASA.
- Nordin, V., & Gillberg, C. (1998). The long-term course of autistic disorders: Update on follow-up studies. *Acta Psychiatrica Scandinavica, 97*, 99-108.
- Oliver, M. (1996). *Understanding disability. From theory to practice*. London: MacMillan Press Ltd.
- Olley, J. G. (1999). Curriculum for students with autism. *School Psychology Review, 28*, 595-607.
- Ostberg, M., & Hagekull, B. (2000). A structural modeling approach to the understanding of parenting stress. *Journal of Clinical Child Psychology, 29*, 615-625.

- Otrebski, W. (2000). Quality of life of people with mental retardation living in two different environments in Poland. In K. D. Keith, & R. L. Schalock (Eds.), *Cross-cultural perspectives on quality of life* (pp. 83-92). Washington, DC: American Association on Mental Retardation.
- Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. *Autism, 9*, 191-212.
- Palmer, D., Fuller, K., Arora, T., & Nelson, M. (2001). Taking sides: Parent views on inclusion for their children with severe disabilities. *Exceptional Children, 67*, 467-484.
- Panerai, S., Ferrante, L., & Zingale, M. (2002). Benefits of the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) programme as compared with a non-specific approach. *Journal of Intellectual Disability Research, 46*, 318-327.
- Pasch, L. A., & Bradbury, T. N. (1998). Social support, conflict, and the development of marital dysfunction. *Journal of Consulting and Clinical Psychology, 66*, 219-230.
- Peeters, T. (2000) The role of training in developing good services for persons with autism and their families. *International Journal of Mental Health, 29*, 44-59.
- Peetsma, T., Vergeer, M., Roeleveld, J., & Karsten S. (2001). Inclusion in education: Comparing pupils' development in special and regular education. *Educational Review, 53*, 125-135.
- Persson, B. (2000). Brief report: A longitudinal study of quality of life and independence among adult men with autism. *Journal of Autism and Developmental Disorders, 30*, 61-66.

- Petito, F., & Cummins, R. (2000). Quality of life in adolescence: the role of perceived control, parenting style, and social support. *Behaviour Change*, *17*, 196-207.
- Phelan, M., Slade, M., Thornicroft, G., Dunn, D., Holloway, F., Wykes, T., Strathdee, G., Loftus, L., McCrone, P., & Hayward, P. (1995). The Camberwell Assessment of Need: The validity and reliability of an instrument to assess the needs of people with severe mental illness. *British Journal of Psychiatry*, *167*, 589-95.
- Piven, J., Palmer, P., Jacobi, D., Childress, D., & Arndt, S. (1997). Broader autism phenotype: Evidence from a family history study of multiple-incidence autism families. *American Journal of Psychiatry*, *154*, 185-190.
- Ponnet, K., Roeyers, H., & Buysse, A. (2001). *Het Autismespectrum Quotiënt*. [The Autism-Spectrum Quotient] (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001), unpublished translation, Ghent University.
- Race, D., Boxall, K., & Carson, I. (2005). Towards a dialogue for practice: Reconciling the social role valorization and the social model of disability. *Disability & Society*, *20*, 507-521.
- Reddon, J. E., McDonald, L., & Kysela, G. M. (1992). Parental coping and family stress I: Resources for the functioning of families with a preschool child having a disability. *Early Child Development and Care*, *83*, 1-26.
- Renty, J., & Roeyers, H. (2004). Quality of services and schools for persons with autism. The client's perspective. *Journal of Intellectual Disabilities Research*, *48*, 423.
- Renty, J., & Roeyers, H. (2005a). Students with autism spectrum disorder in special and general education schools in Flanders. *British Journal of Developmental Disabilities*, *51*, 27-39.

- Renty, J., & Roeyers, H. (2005b). Quality of life in high-functioning adults with autism spectrum disorder: the predictive value of disability and support characteristics. *Manuscript submitted for publication*.
- Renty, J., & Roeyers, H. (in press). Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents. *Child: Care, Health, and Development*.
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. Burgess (Eds.), *Analysing Qualitative Data*. London: Routledge.
- Rogers, S. J. (1998). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology, 27*, 168-179.
- Ruble, L., & Dalrymple, N. (1996). An alternative view of outcome in autism. *Focus on Autism and Other Developmental Disabilities, 11*, 3-14.
- Ruble, L., Heflinger, C., Renfrew, J., & Saunders, R. (2005). Access and service use by children with autism spectrum disorders in Medicaid managed care. *Journal of Autism and Developmental Disorders, 35*, 3-13.
- Ruef, M., & Turnbull, A. (2002). The perspectives of individuals with cognitive disabilities and/or autism on their lives and their problem behavior. *Research and Practice for Persons with Severe Disabilities, 27*, 125-140.
- Rumsey, J., Rapoport, J., & Sceery, W. (1985). Autistic children as adults: psychiatric, social and behavioral outcomes. *Journal of the American Academy of Child and Adolescent Psychiatry, 24*, 465-473.
- Russell, D., & Cutrona, C.E. (1991). Social support, stress, and depressive symptoms among the elderly: Test of a process model. *Psychology and Aging, 6*, 190-201.
- Rutter, M. (2000). Genetic studies of autism: From the 1970s into the millennium. *Journal of Abnormal Child Psychology, 28*, 3-14.

- Rutter, M. (2004). Incidence of autism spectrum disorders: Changes over time and their meaning. *Acta Paediatrica*, *94*, 2-15.
- Saloviita, T., Italinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A Double ABCX Model. *Journal of Intellectual Disability Research*, *47*, 300-312.
- Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child & Family Behavior Therapy*, *19*, 15-32.
- Schalock, R. L. (1994). Quality of life, quality enhancement, and quality assurance: Implications for program planning and evaluation in the field of mental retardation and developmental disabilities. *Evaluation and Program Planning*, *17*, 121-131.
- Schalock, R. L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R. L. Schalock (Ed.), *Quality of Life, Volume I. Conceptualization and Measurement* (pp. 123-139). Washington, DC: American Association on Mental Retardation.
- Schalock, R. L. (1997). *Quality of Life, Volume II. Application to persons with disabilities*. Washington, DC: American Association on Mental Retardation.
- Schalock, R. L. (2000). Three decades of quality of life. *Focus on Autism and Other Developmental Disabilities*, *15*, 116-127.
- Schalock, R. L. (2001). *Outcome-based evaluation*. Second Edition. New York: Kluwer Academic/Plenum Publications.
- Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, *48*, 203 -216.
- Schalock, R. L., & Bonham, G. S. (2003). Measuring outcomes and managing for results. *Evaluation and Program Planning*, *26*, 229-234.

- Schalock, R. L., & Keith, K. (1993). *Quality of Life Questionnaire Manual*. Worthington, OH: IDS Publishing.
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on Quality of Life for Human Service Practitioners*. Washington, DC: American Association on Mental Retardation.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an International Panel of Experts. *Mental Retardation, 40*, 457-470.
- Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Xu, J. C., & Lachapelle, Y. (2005). Cross-cultural study of quality of life indicators. *American Journal on Mental Retardation, 110*, 298-311.
- Schreibman, L. (1988). *Autism*. Newbury Park, CA: Sage.
- Scruggs, T. E., & Mastropieri, M. A. (1996). Teacher perceptions of mainstreaming/inclusion, 1958-1995: A research synthesis. *Exceptional Children, 63*, 59-74.
- Seltzer, M., & Krauss, M. (1989). Aging parents with adult mentally retarded children: Family risk factors and sources of support. *American Journal on Mental Retardation, 94*, 303-312.
- Slade, M., Leese, M., Ruggeri, M., Kuipers, E., Tansella, M., & Thornicroft, G. (2004). Does meeting needs improve quality of life? *Psychotherapy and Psychosomatics, 73*, 183-189.
- Slade, M., Leese, M., Taylor, R., & Thornicroft, G. (1999). The association between needs and quality of life in an epidemiologically representative sample of people with psychosis. *Acta Psychiatrica Scandinavica, 100*, 149-157.

- Sloper, P. (1999). Models of service support for parents of disabled children. What do we know? *Child: Care, Health and Development*, 25, 85-99.
- Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development*, 18, 259-282.
- Snowdon, A., Cameron, S., & Dunham, K. (1994). Relationships between stress, coping resources, and satisfaction with family functioning in families of children with disabilities. *Canadian Journal of Nursing Research*, 26, 63-76.
- Spanier, G. B. (1976). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 38, 15-28.
- Sperry, L., Whaley, K., Shaw, & Brame, K. (1999) Services for young children with autism spectrum disorder: Voices of parents and providers. *Infants and young children*, 11, 17-33.
- Szatmari, P., Bartulocci, G., Bremner, R., Bond, S., & Rich, S. (1989). A follow up study of high-functioning autistic children. *Journal of Autism and Developmental Disorders*, 19, 213-225.
- Taanila, A., Syrjälä, L., Kokkonen, J., & Järvelin, M. R. (2002). Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health and Development*, 28, 73-86.
- Tak, Y. R., & McCubbin, M. (2002). Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease. *Journal of Advanced Nursing*, 39, 190-198.
- Tantam, D. (2000). Psychological disorder in adolescents and adults with Asperger syndrome. *Autism*, 4, 47-62.
- Tantam, D. (2003). The challenge of adolescents and adults with Asperger Syndrome. *Child and Adolescent Psychiatric Clinics of North America*, 12, 143-163.

- Thoits, P. A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of Health and Social Behavior, 35*, 53-79.
- Thorndike, E. L. (1939). *Your city*. Harcourt Brace: New York.
- Trivette, C. M., & Dunst, C. (1992). Characteristics and influences of role division and social support among mothers of preschool children with disabilities. *Topics in Early Childhood Special Education, 12*, 367-385.
- Trute, B. (2003). Grandparents of children with developmental disabilities: Intergenerational support and family well-being. *Families in Society, 84*, 119-126.
- Tsatsanis, K. (2003). Outcome research in Asperger syndrome and autism. *Child and Adolescent Psychiatric Clinics of North America, 12*, 47-63.
- Van Bourgondien, M. E., & Elgar, S. (1990). The relationship between existing residential services and the needs of autistic adults. *Journal of Autism and Developmental Disorders, 20*, 299-308.
- Venter, A., Lord, C., & Schopler, E. (1992). A follow-up study of high functioning autistic children. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 33*, 489-507.
- Walden, S., Pistrang, N., & Joyce, T. (2000). Parents of adults with intellectual disabilities: quality of life and quality of caring. *Journal of Applied Research in Intellectual Disabilities, 13*, 62-76.
- Waldron, N., & McLeskey, J. (1998). The effects of an inclusive school program on students with mild and severe learning disabilities. *Exceptional Children, 64*, 395-405.
- Wallander, J. L., Schmitt, M., & Koot, H. M. (2001). Quality of life measurement in children and adolescents: Issues, instruments, and applications. *Journal of Clinical Psychology, 57*, 571-585.

- Wechsler, D. (2000). *WAIS-III: Wechsler Adult Intelligence Scale: Third Edition*. Lisse: Zwets & Zeitlinger.
- Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism, 6*, 115-130.
- Westling, D. (1996). What do parents of children with moderate and severe mental disabilities want? *Education and Training in Mental Retardation and Developmental Disabilities, 31*, 86-114.
- Wethington, E., & Kessler, R. (1986). Perceived support, received support, and adjustment to stressful life events. *Journal of Health and Social Behavior, 27*, 78-89.
- Whitaker, P. (2002). Supporting families of preschool children with autism. *Autism, 6*, 411-426.
- White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 181-190.
- Whitney-Thomas, J. (1997). Participatory Action Research as an approach to enhancing quality of life for individuals with disabilities. In R. L. Schalock (Ed.), *Quality of Life. Volume II. Application to persons with disabilities* (pp. 181-197). Washington, DC: American Association on Mental Retardation.
- Wing, L. (1996). *The autistic spectrum: A guide for parents and professionals*. Suffolk: St Edmundsbury Press.
- Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews, 8*, 151-161
- Woodbury-Smith, M. R., Robinson, J., Wheelwright, S., & Baron-Cohen, S. (2005). Screening adults for asperger syndrome using the AQ: A

preliminary study of its diagnostic validity in clinical practice. *Journal of Autism and Developmental Disorders*, 35, 331-5.

Young, R., Brewer, N., & Pattison, C. (2003). Parental identification of early behavioural abnormalities in children with autistic disorder. *Autism*, 7, 125-143.

Zager, D., Shamow, N., & Schneider, H. (1999). Teaching students with autism. In D. Zager (Ed.), *Autism. Identification, education, and treatment* (pp. 111-139). New Jersey: Lawrence Erlbaum Associates.