

# Annual Research Review: Conceptualising functional impairment in children and adolescents

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Functional impairment is a key factor in the clinical importance of mental health problems in children. Yet, the nature of impairment and criteria for defining and assessing impairment in childhood disorders has been surprisingly overlooked in much of the literature. The current article examines the extant literature on the conceptualisation, nature and assessment of impairment in childhood disorders. Relations between diagnostic symptoms and functional impairment are discussed together with the influence of impairment on diagnostic decisions and prevalence rates. Several factors influencing impairment in childhood such as culture, development and gender are considered. This article concludes with a discussion of the utility of separating judgements of impairment from specific diagnoses, which is proposed for consideration in the forthcoming DSM-5. **Keywords:** Mental health, quality of life.

## Introduction

For over three decades, the DSM nosology has specified that the diagnosis of a mental disorder can occur only when specific symptom criteria are met and typically when those symptoms result in marked distress or disability that makes the symptoms clinically significant (American Psychiatric Association, 1980, p. 6; 1987, p. xxii; American Psychiatric Association, 1994, p. xxi). In DSM-IV, a mental disorder is defined as a 'clinically significant behavioral or psychological syndrome ... associated with *distress* (a painful symptom) or *disability* (impairment in one or more areas of functioning)'. In contrast, US Public Law 102–321 specifies that children with 'severe emotional disturbance' who are entitled to mental health services are defined as 'persons from birth to 18 who ... in the past year have a diagnosable DSM or comparable psychiatric disorder that *resulted in functional impairment* which ... interfered or limited the child's role or functioning in family, school, or community activities' (US Federal Register, 1993) (*italics added*). Thus, this legal definition, at least in the United States, appears to distinguish between a DSM diagnosis and the consequences of that disorder (i.e. its functional impairment). Within developments for the forthcoming DSM-5, one point of view is presented by the Impairment and Disability Assessment Study Group, who are suggesting that the symptoms of disorder be separated from their consequences (DSM-5 Impairment and Disability Assessment

Study Group, 2011). Although this approach may possess merit, it would reflect a marked departure from DSM-IV and its precursors in which these two facets have been intimately intertwined.

In contrast to the DSM, the ICD-10 has already moved to disentangle diagnoses and their consequences. In 2007, the WHO published the International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY; WHO, 2007) which was designed to complement the ICD-10 and to provide a comprehensive framework to classify the functional effects of diseases (Lollar, 2008). The system organises aspects of impairment across three areas: body (including physical and psychological functions), activity (reflecting the ability to perform tasks) and participation (reflecting the extent to which a child becomes involved in life). Environmental caveats are also coded so that a child's level of functioning as a consequence of symptoms is defined within the context of the environment in which he or she exists.

Such a movement for DSM-5 will likely have implications for the definition of 'caseness' whether in reference to the provision of clinical and educational services for those in need of mental health services or to epidemiological surveys documenting the prevalence of mental disorders in community surveys. As a result, the measurement of disability and impairment will take on added importance in the years ahead.

In this paper, we discuss the notion of impairment as it relates to mental health of young people. We consider definitions and assessment as well as the influence of impairment criteria on assessment of

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prevalence of mental disorders. We also consider several factors that affect impairment including developmental considerations and contextual factors. These deliberations allow us to conclude with a discussion of issues regarding impairment that are currently being considered by the DSM-5 committees.

### Distress, impairment, and quality of life

Although the terms are sometimes used interchangeably, experts generally distinguish among these related, but distinct constructs. *Distress* refers to a personal and subjective sense of malaise and negativity and is primarily an emotional reflection. Of relevance to diagnostic criteria, some mental disorders contain personal distress as a core component of the disorder (e.g. anxiety, depression) while in others the distress arises as a consequence of the disorder [e.g. attention deficit hyperactivity disorder (ADHD), substance abuse]. *Functional impairment* is also often measured subjectively, but the construct reflects more overt and objective aspects than does the concept of distress. Impairment generally refers to ways in which symptoms interfere with and reduce adequate performance of important and desired aspects of a child's life. Impairment can be seen across several areas of functioning. Most common conceptualisations indicate three areas of impairment within family, school and social domains (Achenbach & Edelbrock, 1979). Empirical data have supported these domains. For example, a factor analysis of several specific areas of interference identified three dimensions: interference with parents, peers and education (Ezpeleta, Keeler, Alaatin, Costello, & Angold, 2001). As mentioned above, the ICF-CY codes impairment in the areas of physical (including mental) functioning, activity and participation in society.

*Quality of life* is a more global, subjective construct than either distress or impairment and reflects the overall positivity with which individuals view their state and circumstances. It comprises an amalgam of physical, psychological, cognitive and social functioning (Danckaerts et al., 2010). Thus, although the three constructs, distress, impairment and quality of life, are strongly related and are often used interchangeably, they each reflect slightly different aspects of the possible effects of symptoms.

### Relationship between symptoms and impairment

One of the key issues for a system of classification, an issue that is currently being considered by the DSM-5 Impairment and Disability Assessment Study Group, is the extent to which symptoms and their associated impairment can be disentangled. Empirically, this issue partly translates to consideration of the association between symptoms of psychopa-

thology and functional impairment. If the two are perfectly correlated, then information obtained from measures of impairment is superfluous as it provides no additional information over that contained within measurement of symptoms (Danckaerts et al., 2010). However, if the two can be demonstrated to be empirically distinct, then determination of clinical disorder may benefit by data derived from both constructs.

Although data from child samples are limited, measures of functional impairment and symptom counts indicate moderate linear relationships (Bird, Yager, Staghezza, Gould, et al., 1990; Keenan, Wroblewski, Hipwell, Loeber, & Stouthamer-Loeber, 2010; Pickles et al., 2001). For example, in an interview study of over 2,000 adolescents, information was separately obtained about symptoms and concomitant impairment across 15 areas of functioning (Pickles et al., 2001). For each of the three disorders examined, major depression, conduct disorder (CD) and oppositional disorder, the number of symptoms was linearly related to the extent of impairment. Studies that have quantified relationships between symptoms and impairment have generally reported moderate correlations between them (Allen, Lavalley, Herren, Ruhe, & Schneider, 2010; Kutash, Lynn, & Burns, 2008; Storch et al., 2010; Winters, Collett, & Myers, 2005). For example, Storch et al. (2010) reported correlations ranging from .14 to .41 between measures of children's symptoms of OCD and both children's and parents' ratings of impairment across various domains. Among children with separation anxiety disorder, correlations between number of symptoms and parent or child rated impairment ranged from .34 to .41 (Allen et al., 2010).

A closely related question is the extent to which diagnostic thresholds reflect a cutpoint along a continuum or a qualitatively unique entity. From the perspective of impairment, if mental disorders represent unique entities that lead to functional impairment, then it should be possible to demonstrate that those scoring above diagnostic thresholds will be considerably more impaired than those scoring below (i.e. more than a linear increase). To examine this issue, the relationship between symptoms of oppositional/CD and impairment were assessed in a longitudinal study of almost 2,500 girls initially aged 5–8 years and followed to age 15 (Keenan et al., 2010). Results were mixed. There was a direct relationship between number of symptoms and degree of impairment according to reports from parents, teachers and the girls. With each additional symptom, there was an increase in impairment, pointing to a lack of specificity of the threshold. However, according to parent and to a lesser extent teacher reports, there was a tendency for a slightly greater increase in impairment once three symptoms were recorded, suggesting a threshold at which the impact of symptoms might escalate. A slightly

different method based on multiple regression was used with a sample of adolescents (described above) to determine the relationship between number of symptoms and impairment above versus below diagnostic thresholds for each of three disorders (Pickles et al., 2001). None of the disorders [Major depressive disorder (MDD), Oppositional defiant disorder (ODD), CD] was associated with a greater than expected increase in impairment above the diagnostic threshold. Similar results have been reported among preschool populations with ADHD where impairment above and below diagnostic threshold appears to differ linearly (Egger, Kondo, & Angold, 2006).

The lack of perfect relationship between symptoms and impairment suggests that it should be possible to identify children who meet symptom-based diagnostic criteria for a form of psychopathology but do not show significant levels of functional impairment, while other groups may be identified who are significantly impaired but do not meet symptom criteria for a given disorder. Empirical evidence from several studies supports this prediction (Costello, Angold, & Keeler, 1999; Ezpeleta et al., 2001; Pickles et al., 2001). One of the most widely cited studies involved children from the Great Smoky Mountains cohort (Angold, Costello, Farmer, Burns, & Erkanli, 1999). Over 1,000 children aged 9–11 years and a caregiver were assessed using the Child and Adolescent Psychiatric Assessment (CAPA; Angold & Costello, 2000), a structured interview that codes for the presence of diagnoses based on emotional and behavioural symptoms. The interview separately allows for the determination of psychosocial impairment across 17 areas as a consequence of symptoms. Overall, it was found that 12% of the sample had a diagnosis (based purely on symptom criteria) but were not significantly impaired, while 14% were significantly impaired but did not meet criteria for a diagnosis based on symptoms. Of practical importance, impairment related to symptoms was a more important determinant of service use than was simple diagnosis alone.

Finally, a few longitudinal studies have demonstrated independent prediction of future difficulties from both symptom counts and functional impairment (Costello et al., 1999; Pickles et al., 2001). In the adolescent study described previously (Pickles et al., 2001), regressions were used to determine the extent to which disorders 18 months later could be predicted by baseline data. Diagnoses of MDD were predicted only by symptoms at baseline – impairment did not add to the prediction, indicating that impairment information did not provide unique information about the development of future depression, at least in this one study. In contrast, both symptoms and impairment at baseline contributed independent variance to prediction of CD and ODD 18 months later, indicating the independent importance of both constructs to externalising disorders.

### **Distress and impairment associated with specific disorders**

It is likely that both the extent of distress and impairment and their ratio will vary between particular mental disorders. A logical assumption is that distress is likely to be higher among internalising disorders while functional impairment will be more extensive among externalising disorders. Empirical evaluation in young people has been limited, and has mostly, but not always supported this assumption.

In an early study of 430 children aged 7–11, externalising disorders (ADHD, CD and ODD) were associated with markedly greater impairment than internalising disorders (depression and anxiety; Costello & Shugart, 1992). It was unclear how determination of impairment was made in this study but it appeared to be based on an amalgam of interviewer-rated global functioning and paediatrician-rated factors including family stress and school performance. Hence, externalising disorders appear to produce greater impairment based on ratings from an external observer. In other words, they are associated with greater disruption to others.

In a study of the prevalence of disorders among the Virginia Twin Sample, DSM-III-R diagnoses were based on interviews with the CAPA among 2,700 twins aged 8–16 years and their parents (Simonoff et al., 1997). As incorporated into the CAPA, impairment was determined across 15 areas of functioning based on either parent or child report. Children meeting symptom-based diagnoses for internalising were less impaired than children meeting diagnoses for externalising disorders. More specifically, the least impairment was associated with specific phobias, followed by separation anxiety and social anxiety disorder and the greatest impairment was associated with ODD followed by CD and ADHD.

Quite different patterns were reported in an evaluation of 1,400 children aged 9–13 years from the Great Smoky Mountains Study in which data from interviews also using the CAPA were used to examine life interference associated with a variety of diagnoses (Ezpeleta et al., 2001). Overall, depression and CD were associated with the greatest levels of impairment. But there were differences in the patterns of specific interference. Family interference was greatest for children with anxiety, ODD and depression, whereas educational interference was most likely to be reported for children with ADHD, CD and substance use. Peer relationships were least likely to be impacted by all disorders, although this finding is surprising given the extensive data on interference with peer relationships associated with several disorders (Gazelle, Olson Workman, & Allan, 2010; Puig-Antich et al., 1993; Riley, Ensminger, Green, & Kang, 1998).

Simple comparison of impairment across diagnoses may be confounded by differences in diagnostic

thresholds. For example, it has been shown that functional impairment is more likely to be demonstrated by children demonstrating subthreshold levels of behavioural symptoms than subthreshold levels of emotional symptoms (Costello & Shugart, 1992). This difference may be a result of the extent to which functional impairment is integrally incorporated within diagnostic decisions for different disorders. For example, in the adolescent sample reported by Pickles et al. (2001), the diagnostic threshold for major depression was very closely tied with impairment whereas the threshold for CD was a less precise marker of impairment. Similarly, among their sample of children who failed to meet diagnostic criteria for a disorder, Angold et al. (1999) found that disruptive symptoms were a far more common source of impairment than were emotional symptoms. This point is strongly illustrated by data from the MECA study in which inclusion or exclusion of a stringent impairment criterion in determining diagnosis had a far more dramatic effect on anxiety disorders (3.2% vs. 39.5%) than disruptive disorders (3.7% vs. 14.3%; Shaffer et al., 1996).

### Measurement of impairment in children

In an article entitled 'How Specific is Specific Impairment', Bird and colleagues identified three primary measurement strategies for the definition of impairment: (a) measures that incorporate the symptoms and their correlates into the definition of disorder, (b) specific impairment measures associated with each diagnosis, and (c) global omnibus impairment measures (Bird et al., 2000). Each of these measurement strategies and their strengths and weaknesses will be commented upon briefly.

#### *Measures that combine symptoms and their consequences*

Representative of measures that intertwine symptoms and impairment are some of the major structured diagnostic interviews such as the CAPA (Angold & Costello, 2000, and its various revisions). For example, for the diagnosis of social anxiety disorder, symptoms including fear, self-consciousness, embarrassment, and concern about the appropriateness of one's behaviour while interacting with unfamiliar people are queried. In response to several questions tapping situations in which a child might display social anxiety, the interviewer is asked to assess the impairment associated with the various symptoms. Ratings range from 0 to 4. A '0' indicates that the symptoms are not intrusive and do not interfere with everyday functioning; a '1' indicates that the fear is intrusive into at least one activity and uncontrollable at least some of the time; a '2' indicates that the social anxiety is intrusive into at least two activities and uncontrollable at least some of the time; a '3' suggests that the social anxiety is intrusive

into most activities and nearly always uncontrollable; and a '4' indicates that the child has not been in such a situation during the past 3 months because parent helped him/her to avoid it, but parent reports that extreme anxiety would occur if the child had been in the situation. As can be seen, CAPA first determines if the symptoms are present and then assigns them an intensity level reflecting the impairment associated with the present symptoms. Consistent with current DSM criteria, the disorder is dependent upon both symptoms and impairment being present. The CAPA, though a highly reliable and valid interview, has been criticised not only for its conflation of symptoms and impairment but also because of its length and the level of clinical training needed for its raters (Bird et al., 2000; Winters et al., 2005).

#### *Diagnosis specific measures*

Representative of the more specific impairment measures are those found on other structured or semistructured diagnostic interviews such as the NIMH DISC-2.3 (DISC; Schwab-Stone et al., 1996; Shaffer et al., 1996) and the Anxiety Disorders Interview Schedule for DSM-IV Child and Parent Versions (ADIS; Silverman & Albano, 1996). In both of these instruments, the symptoms are assessed independent of impairment but both are determined from the same instruments and the same informants. The DISC is a highly structured diagnostic interview that was designed to determine symptom criteria for all of the major psychiatric disorders in children and adolescents. Separate interviews for children and parents are available. Following each of the DISC modules, specific impairment related to the symptoms for that disorder is ascertained. Typical questions for the parent interview include: 'Have the (identified symptoms) made him/her very upset?' 'Have the (identified symptoms) caused a problem with how he or she gets along with people at home?' 'Have these things (identified symptoms) caused problems for him or her at school?' And, 'Have these things (identified symptoms) caused a problem with how he or she gets along with friends or others his or her age?' These same questions, or very similar ones, are repeated after each diagnostic module and are included on both the parent and child forms.

Similarly, on the semistructured ADIS, impairment questions follow each of the diagnostic modules. Thus, question such as the following are asked: 'Now I want to find out how much you feel this problem (e.g. ADHD, social anxiety disorder, etc.) interferes with your child's life. That is, how much has it *interfered* with your child's friendships, caused problems at school or at home, and stopped your child from doing the things he or she would like to do? If you could rate the degree of interference from 0 to 8, where 0 is *Not at all*, 4 is *Some*, and 8 is *Very, very much*, what would you say? Likewise, the

children are asked: 'Okay, I want to know how much you feel this problem has messed things up in your life? That is, how much has it messed things up for you with friends, in school or at home? How much does it stop you from doing things you would like to do? Tell me how much by using the Feelings Thermometer (0 to 8 rating scale) we discussed earlier, okay?'

Both the DISC and the ADIS have been shown to be highly reliable and valid instruments for the diagnosis of diverse child psychiatric disorders (Silverman & Ollendick, 2005, 2008), although the reliability and validity of the impairment ratings has generally not been examined independently. Furthermore, both interviews require the presence of interference/impairment for diagnostic decision making. Thus, symptoms and their level of interference are conflated in these systems as well. Of course, not unlike the CAPA, these instruments were designed to include both symptom and impairment ratings in as much as they were attempting to capture both facets of disorder as required by the DSM-IV. However, the two facets of disorder can be disentangled, though rarely has this been done. As described earlier, some research has examined relationships between diagnostic thresholds and impairment (Egger et al., 2006; Keenan et al., 2010; Pickles et al., 2001), but further research examining the requisite number of DSM symptoms, their associated impairment levels, and their relations to more global impairment ratings is needed.

As one example of this needed research, Whiteside (2009) recently adapted the Sheehan Disability Scale (Sheehan, 1996) to assess child and parent impairment associated with different childhood anxiety disorders. The Child Sheehan Disability Scale (CSDS) was designed to measure the extent to which the child's anxiety symptoms interfere with daily functioning in the three primary areas of family, school and peer relations. The scale is very brief and completed independently by the child (three items) and the parent (five items) and not by a clinical interviewer as with the CAPA, DISC and ADIS. Interestingly, the parent version includes items not only about interference for the child but also for the parents. Items are measured on an 11-point scale ranging from 0 (*not at all*) to 10 (*very, very much*). Illustrative examples are 'How much have your fears and worries messed things up with friends' for the child, 'How much have your child's symptoms disrupted your child's social life' for the parent about the child, and 'How much have the symptoms disrupted your own social life' for the parents about themselves. Child-reported interference ratings correlated positively with parent-reported child and parent interference ratings; moreover, the two parent ratings were positively related to one another. All three interference ratings were also related to clinician interference ratings obtained on the ADIS and the ratings varied significantly for the different anxiety disorders: the greatest impairment was associ-

ated with OCD and social anxiety disorder, followed by separation anxiety disorder, and then generalized anxiety disorder. Findings suggest that the CSDS is not only a reliable and valid measure, it is also time efficient and clinically sensitive in that it secures information directly from the child and the parent which can then be related to that obtained from a clinician.

### *Omnibus impairment measures*

The third type of measure recommended by Bird et al. (2000) was the omnibus global impairment measure. These measures, long in vogue, have been examined in a multitude of studies (see Kutash et al., 2008; Winters et al., 2005 for reviews). The most popular and widely used of these measures has been the Children's Global Assessment Scale (CGAS, Shaffer et al., 1983). The CGAS, completed by independent clinical raters, was used in many of the field trials for DSM-IV to determine impairment associated with various numbers of symptoms and severity of symptoms for diagnostic thresholds (see Lahey et al., 1994, for ADHD; Frick et al., 1994 for ODD). The scale, ranging between 0 and 100, generally uses a cut-off score of 60 to define impairment and is described as follows: 'In some situations the problems are noticeable to anyone, but in other situations the child could seem fine'. This threshold for clinically significant impairment was based on findings that a score of 60 or less best predicted those youth in a representative community sample who had received mental health services (i.e. those in need of treatment). It is evident that the CGAS, like the other measures of impairment, conflate symptoms with levels of impairment. In fact, the CGAS is directly related to presence of diagnosis which in turn is related to symptom count.

Recently, Bird et al. (2005) developed another omnibus impairment scale: The Brief Impairment Scale (BIS). The BIS consists of 23 items scored along three functioning domains: interpersonal relations (parents, siblings, peers, teachers and other adults), school/work (attendance, performance, responsibility), and self-fulfilment (sports participation, hobbies, self-care and enjoyment). Scores range from 0–3 (no problem, some problem, a considerable problem, a serious problem). It is administered to parents by a clinician.

Quite obviously, several impairment measures have been developed for children and adolescents and are in routine clinical use. As noted by Bird et al. (2000), they vary from the global omnibus measures to those that are more specific and disorder-related to those that are embedded within the symptom picture of the disorders themselves. To a large extent this state of affairs is related to our current nosology which has specified that diagnostic decisions should be based not only on symptoms but also on the consequences (i.e. the impairment or interference)

associated with those symptoms. In the DSM-IV, 'caseness' is largely determined by the confluence of these two vectors (e.g. Shaffer et al., 1996). Epidemiological work tells us that disorders are much more prevalent in the community when impairment or disability requirements are not applied. As one example, using the DISC with a Canadian sample of 15-year-olds, Romano, Tremblay, Vitaro, Zoccolillo, and Pagani (2001) reported that 30.2% of females and 15.2% of males reported at least one disorder on the DISC when only symptom criteria were used; conversely, when impairment criteria on the DISC were included these rates decreased to 15.5% and 8.5% for females and males, respectively. Similarly, when the mothers were used as the informants, the rates were 19.6% for the females and 13.6% for males; once again, these rates were reduced to 11.0% and 10.7% when impairment was required. Quite clearly, differences in 'caseness' were obtained depending on whether impairment was a required criterion. Even more dramatic data are reported by Shaffer et al. (1996) from the large MECA study. When diagnoses were based on only symptom counts, over half of the population of children (9–17 years; 50.6%) met criteria for a mental disorder whereas under the most severe impairment restrictions, this number reduced to 5.4%. Similar results are reported in other studies across the spectrum of childhood. Relative to the prevalence of disorders based on symptom criteria only, prevalence of mental disorders reduce markedly when diagnostic decisions require a moderate or greater level of impairment (Canino et al., 2004; Carter et al., 2010; Lavigne, LeBailly, Hopkins, Gouze, & Binns, 2009; Merikangas et al., 2010). Of course, increases in prevalence are not necessarily a problem and the extent to which they are considered problematic depends on various factors such as the limits on available services and the degree of stigma associated with diagnoses. In addition, as noted by Spitzer and Wakefield (1999), prevalence of disorder can be reduced by raising the symptom severity criteria for given diagnoses.

## Factors influencing functional impairment

### Context

The close interrelationship between impairment and symptoms suggests that the severity and number of symptoms will provide the strongest influence on levels of impairment. However, the clinical and epidemiological findings reviewed above indicate that this is not the only influence and that a considerable proportion of variance in level of impairment remains to be explained by other factors (Rapee & Spence, 2004; Storch et al., 2010).

As noted earlier, the ICF-CY includes codes for environment within its system for categorising functioning. Decisions about functioning are made

while taking environmental constraints and influences into account (WHO, 2007). The meaning and impact of symptoms must vary according to the context in which they are displayed. A sobering example is highlighted in a descriptive study of Masai children from the sub-Saharan during a severe drought in 1974 (DeVries, 1984). Infants were divided on the basis of temperamental behaviours into 'easy' and 'difficult' groups. While these behaviours are not, strictly speaking symptoms, the marked overlap between temperament and symptoms of disorder (Costello, Egger, & Angold, 2005; Nigg, 2006; Rapee & Coplan, 2010) points to their similarities. Contrary to expectation, there was greater mortality among infants showing less irritable (so-called 'easy') behaviours. The author argued that the irritable children had attracted more attention and food through their overt distress, while parents ignored the easy-going children under the difficult circumstances increasing their risk of death. Thus, although these easy-going children would normally be viewed as the better adapted and higher functioning, within the context of a drought, their behaviours resulted in greater impairment. To provide a different example from our own lab, 29 children meeting DSM criteria for anxiety disorders and 18 nonclinical children aged 7–16 years were compared on their performance on a driving simulator (Johnson, 2001). Clinically anxious children demonstrated fewer accidents than nonclinical children, indicating that within particular contexts, clinical levels of anxiety can be adaptive. Other research has shown that a combination of behaviours and contextual demands predicts adolescent adjustment better than do the behaviours alone (Talwar, Nitz, & Lerner, 1988, cited in Lerner, 1993).

During childhood one of the obvious sources of contextual influence is the family and especially the parents (WHO, 2007). Although the concept of 'goodness of fit' has been generally applied to consideration of temperament, it can just as easily relate to symptoms of psychopathology, given the close interrelationship between the two (Nigg, 2006; Rapee & Coplan, 2010). Goodness of fit refers to the hypothesis that a particular temperament (or set of behaviours) will be more or less problematic depending on the context in which children find themselves. Although in theory this idea could be applied to any context, it has most commonly been applied to the family context. As an example, Super and Harkness (1982) describe a comparison between infants from suburban Boston and from Kokwet, a farming community in Kenya. While the Boston infants are highly regulated from an early age, with set routines, especially for sleep/wake cycles, the infants in Kokwet spend most of their time in direct contact with the mother, riding on her hip, playing and sleeping with her. Therefore, poorly regulated infants who show sleep disturbance and frequent wakening produce far greater distress and disruption

in Boston than in Kokwet. Children who have difficulties with behavioural regulation are considered 'difficult' in Boston but not in Kokwet.

A related idea referred to as accommodation suggests that certain families will facilitate symptoms by adjusting their behaviour and supporting or reinforcing the symptoms (Amir, Freshman, & Foa, 2000). Research has demonstrated the negative effect that family accommodation has on the treatment of childhood OCD (Merlo, Lehmkuhl, Geffken, & Storch, 2009). It has also been shown that accommodation is a significant predictor of functional impairment from symptoms of OCD across home, school and social domains, even after controlling for severity of symptoms (Storch et al., 2010). Thus, a child living within a family context that accommodates their rituals and avoidance will show greater impairment from these symptoms than a child living with a family that does not accommodate. The authors speculate that accommodation may limit the child's ability to learn to cope with the symptoms, thereby increasing the extent to which symptoms affect other aspects of the child's life.

Along similar lines, parents and families may vary considerably in the extent to which their own lives are impaired by their child's symptoms, based on factors such as family/parental resilience, coparental relationship (Majdandžić, de Vente, Feinberg, Aktar, & Bögels, in press), family and marital functioning, etc. For example, childhood separation anxiety disorder may cause parents in some families but not in others, to miss work, not to sleep together anymore as one of the parents sleeps with the child, or to lead to marital discord regarding how to respond to the child's fear. As a result, some assessment measures assess not only interference for the child but also for the parents (Sheehan, 1996; Whiteside, 2009).

### Culture

One of the most pervasive forms of context is the culture in which a child develops. Culture is used here in its broadest sense referring to the behaviours, customs, and beliefs of particular groups of people, including local variations. Several hints in the literature suggest that the extent to which symptoms are impairing may be influenced by discrete cultural factors. For example, some early research demonstrated small but interesting differences in the attitudes of parents and teachers from Thailand and America to internalising and externalising behaviours (Weisz et al., 1988). While American adults were equally likely to believe that internalising and externalising child behaviours required help, Thai adults were slightly more likely to suggest help for externalising than internalising behaviours.

Some specific work in this area has focussed on symptoms of social anxiety disorder such as social

withdrawal. In a model of the development of social anxiety disorder, Rapee and Spence (2004) argued that varying degrees of acceptance of socially withdrawn behaviours by different cultures will affect the extent to which these behaviours impair the individual's life and hence affect rates of the clinical diagnosis. In support of this suggestion, data have shown that socially withdrawn behaviours are more impairing in Western-influenced than Eastern-influenced groups. For example, in a comparison of 228 Chinese Canadian and 367 European Canadian children aged 9–13 years, shyness was related more strongly to peer rejection and victimisation among the European than the Chinese background children (Chen & Tse, 2008). Similar results were reported in a study of over 1,500 children in grades 5 and 6 from four different countries (Chen et al., 2004). Among Chinese children, shyness was positively related to academic achievement and was unrelated to perceived social competence, whereas shyness was negatively related to perceived social competence among Canadian and Brazilian children and was unrelated to academic achievement among Canadian and Italian children. A more direct examination of functional impairment related to symptoms of social anxiety in a young adult sample demonstrated a significantly lower correlation between symptoms of social anxiety and life impairment among students from East Asian countries than students from Western countries (Rapee et al., 2011). Further, in response to hypothetical descriptions of people showing characteristically reticent versus outgoing behaviours, students from East Asian countries predicted less impact and impairment from reticent behaviours on social and career functioning than did the Western students.

### Development

A substantial body of literature now exists regarding the extent to which the prevalence of mental disorders varies with development or age in childhood (for reviews see Angold, Erkanli, Silberg, Eaves, & Costello, 2002) although concomitant discussion of developmental influences on impairment is lacking. The prevalence of mental disorders (and their symptoms) in preschool children has received recent attention (e.g. Costello et al., 2005; Lavigne et al., 2009; Sterba, Egger, & Angold, 2007; Strickland et al., 2011; Wakschlag et al., 2007). This literature has investigated developmental differences in both the prevalence and type of mental disorders in the early years. Of course, assigning diagnoses to young children has been an issue of some debate. Concerns have included, the frequency of change at younger ages, the potential for negative labelling, and the difficulty in distinguishing young children's problems from those of the parents and family (see Egger & Angold, 2006).

Contrary to these arguments, a growing body of empirical data supports the existence of mental disorders among young children. For example, factor-analytic approaches among large community samples and the use of structured interviews among clinical or mixed samples, have consistently pointed to the existence of diagnostic groups quite similar to those found in older children and adults (e.g. Lavigne et al., 2009; Sterba et al., 2007; Strickland et al., 2011; Wilens et al., 2002). In addition, prevalence rates of mental disorders identified in young children appear to be quite similar to those of older children and adults (see Egger & Angold, 2006). Finally, several studies have shown that mental disorders identified in young children predict later functioning and later mental disorders, pointing to the value of identifying mental disorders early in life.

An important issue to consider is the measurement of impairment at different ages. As many self-report measures are inappropriate for children under age 8 years, most impairment research in younger children relies on clinician, teacher or parent report, whereas impairment research in older children tends to include child report as well as reports from their caregivers. Therefore, if one wishes to compare levels of impairment across early development, this generally relies on comparison of reports from observers (such as caregivers or parents) as it is not possible to compare reports of impairment from older children with self-reports from children below the age of 8. As a result, compared to older children, the assessment of impairment among younger children is more likely to be affected by the impact that it has on others (e.g. the parent) and by the parent's own psychopathology and tolerance. For example, a child with feeding difficulties may be reported as 'impaired' by a parent who struggles with their own anxieties and eating issues but not by a parent for whom these issues are not important. The impact of the disorder on the parents and family may also contribute to impairment ratings at later stages of development (for example the effect of an addicted or socially isolated adolescent), but is likely to be less as the child matures and increases their differentiation from the family.

Second, areas in which impairment can occur vary with development and age. Normal development consists of a number of stage-salient tasks that must be negotiated and mastered (Bosquet & Egeland, 2006). Examples include affect regulation in infancy, management of impulses in preschool, adjustment to school environment and the development of friendships in middle school, transition to secondary school and the development of same-sex and heterosexual friendship in adolescence (see Bosquet & Egeland, 2006). One of the most salient differences between younger and older children with respect to areas of impairment is that young children generally have fewer unstructured interactions with peers.

Further differences in academic and social demands as children develop, such as completing homework, negotiating school hierarchies, and the commencement of dating in adolescence are likely to affect particular domains of impairment. From this it follows that symptoms of mental disorders are likely to have different consequences at different ages. For example, symptoms of social anxiety disorder will be less impairing in young children who do not need to interact with peers on a regular basis than in adolescents who have more complex social interactions (Rapee & Spence, 2004). Similarly, test anxiety or ADHD are likely to become increasingly impairing as academic demands increase (Bögels et al., 2010). Given these likely differences, it is somewhat surprising how few studies have focused on developmental differences in areas of impairment.

One early study that addressed differences across age assessed impairment in children aged 6–16 from a representative sample of 3,294 children in Ontario (Sanford, Offord, Boyle, Peace, & Racine, 1992). The following impairment areas were assessed: (a) peers, (b) teachers, (c) family, and a combined overall social functioning score based on these three domains, and (d) schoolwork, (e) student, and (f) grade, and a combined overall school functioning score. Finally, a total impairment score was calculated. At age 6–11, parent and teacher reports of impairment were assessed, while at age 12–16, parent and youth reports were assessed. Across all domains, parents reported lower impairment than teachers or youth. The differences were striking, with teachers reporting much higher impairment than parents in 6- to 11-year-olds and youth reporting much high impairment than parents at ages 12–16. The authors also reported a complex age by gender interaction. In the younger age group, boys showed higher rates of social, school and overall impairment, especially when the teacher was the informant. In the older age group, girls reported higher social impairment than boys who in turn reported higher school impairment than girls. In sum, the results of this study suggest that patterns of impairment vary with developmental level depending on gender and area of impairment.

Wille, Bettge, Wittchen, and Ravens-Sieberer (2008), compared impairment in children aged 7–10 versus 11–17 using a representative sample of 2,863 German families from the BELLA study. Impairment was measured by a supplement to the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) that measures symptoms of psychopathology in children. The presence of severe or definite problems in the area of emotions, concentration, behaviour, or being able to get along with other people were measured, as well as associated distress or impairment in the areas of home life, friendships, classroom learning and leisure activities. Once again, parents were the only consistent reporters across both age groups. Despite the fact that parents rated children (especially boys) as having significantly more

symptoms than adolescents, no differences in parents' perceived distress or impact of these difficulties in children versus adolescents were found. Note that Wille et al. (2008) measured impairment related to symptoms of psychopathology, whereas Sanford et al. (1992) measured impairment independently of symptoms. Note also that Wille et al. (2008) statistically tested age differences in parent report, whereas Sanford et al. (1992) focused on the differences in age groups between teacher reports in the younger age group and adolescent self-report in the older group. Therefore, directly comparing these studies is difficult as differences in patterns of impairment between children and adolescents could be due to differences in measurement and testing, as well as differences in the population culture (Canada vs. Germany).

There is a hint in the literature that the importance of functional impairment may change across development. In a longitudinal high-risk (low SES) sample of 155 children who were followed from birth to age 17.5, Bosquet and Egeland (2006) studied the relationship between what they referred to as 'competence' and the development of anxiety. The concept of competence is to a large degree, the inverse of impairment and was measured by teacher-rated social competence (effectiveness in the peer group), self-esteem (the child's ability to enjoy and benefit from social and academic activities) and work habits. A score for childhood competence was calculated by combining these three areas across kindergarten and first grade. Childhood competence significantly predicted anxiety symptoms in preadolescence ( $\beta = -.39$ ). In later stages of development, however, competence did not predict significant variance in later anxiety. The authors argued that impairment and anxiety may be more integrally intertwined in earlier stages of development through an influence of poor competence on global negative self view. However, by adolescence young people are better able to recognise impairment in one area of life without this distorting their view of their total self. This set of results suggests that the meaning of functional impairment might be different at different stages of development.

Overall, there are very few studies that have shed light on developmental differences in impairment. Due to their varied methods, it is not possible to derive clear conclusions about the influence of developmental factors on functional impairment. Clearly, considerably more research is needed to systematically study developmental differences in impairment, in the context of different informants, domains of functioning, and child gender.

### Gender

Differences in gender roles and expectations as well as evolutionarily based sex differences may influence the impairment arising from symptoms of mental

disorders in a number of ways. As one example, in a study of disruptive behaviour disorders in a school population, an indication for greater social impairment was reported for girls with ODD than for boys with ODD, according to teachers' reports. This difference makes sense if one assumes that externalising behaviours are more inconsistent with gender roles for girls, therefore leading to more social problems (Carlson, Tamm, & Gaub, 1997). Such differences in impairment based on gender have been reported in both community and clinical populations.

In several community samples, children's impairment varied both as a consequence of the child's gender and the informant source (parents, teachers and children). In the representative sample from the BELLA study, for example, severe functional impairment was found in approximately 10% of the girls according to both child and parental reports. For boys, however, parental reports indicated almost 15% of the boys as severely impaired, whereas based on self-reports only 6% of the boys reported impairment (Wille et al., 2008). Further differences between boys and girls are found when examining specific areas of impairment. Overall, according to parents and teachers, boys show higher levels of school-related impairment than girls. In contrast to impairment in academic realms, girls generally seem to self-report greater impairment than boys in the social area (peers and/or family; Ezpeleta et al., 2001; Sanford et al., 1992; Wille et al., 2008). However, direct comparisons between these studies are difficult, as the reported gender differences varied with age and informant. Differences in the ratings of impairment between various informants are likely to be influenced (a) by the type of problems experienced (i.e. in general boys experience more externalising problems than girls, whereas girls experience more internalising problems than boys, for which the impact may be less apparent to others; Wille et al., 2008) and (b) by the different contexts in which the informants interact with the child (demands in the school setting are dissimilar to demands in the home setting; Sanford et al., 1992). Therefore, information about impairment from parents, teachers and children will reflect quite different perspectives, needs and contexts and should all be taken into account in the assessment of impairment (Sanford et al., 1992; Wille et al., 2008).

Gender differences in impairment are considerably less apparent among clinical populations. This is partly due to the fact that children are generally referred for services only after they reach a particular impairment threshold. Second, given the marked gender differences in mental disorders, it is much harder to tease apart the influence on impairment of gender and symptoms among clinical populations. As an example, Greene et al. (2001) failed to find major differences in overall social impairment between boys and girls with ADHD. The only small differences found were that girls showed greater social impairment in spare time activities whereas

boys showed more social impairment at school. Similarly, in a study with juvenile delinquents, McCabe, Lansing, Garland, and Hough (2002) found no significant gender differences in impairment according to parental ratings. A similar lack of gender differences was shown in a study based on a clinical population with an internalising disorder (Allen et al., 2010). Among a sample of children with separation anxiety disorder, no significant gender differences in functional impairment were shown according to either self or parent reports.

In summary, gender differences in impairment are found in community samples according to both self- and observer reports. However, interpretation of these differences is difficult, as they vary with age, informant and domain of impairment. When gender differences in impairment are compared in clinical samples, where boys and girls are experiencing the *same disorders*, these differences mostly disappear. This point is clearly indicated in a meta-analysis of gender differences in ADHD (Gaub & Carlson, 1997). Among nonreferred samples with ADHD, boys are more impaired than girls; however, within clinical samples, boys and girls with ADHD showed similar levels of impairment.

### **Impairment and the diagnosis of mental disorders – considerations for the DSM-5**

As part of the DSM-5 revision, attention is being given to two features of impairment. First is the validity of embedding impairment within the diagnostic criteria, and second is assessment of impairment in ways that are not conflated with symptom severity (see Narrow & Kuhl, 2011).

In terms of the first issue, as described earlier, the *DSM-IV* (APA, 1994) requires distress or impairment as an integral component of its definition of mental disorder. This is generally consistent with definitions in *DSM-III* and *DSM III-R*. In *DSM-IV*, the concept of distress/disability was directly incorporated into the criteria sets for a large number of diagnostic categories, primarily to offset 'false positives', albeit without empirical justification (Spitzer & Wakefield, 1999). That is, the criterion was developed partly out of a need to establish thresholds for diagnoses in order to manage prevalence rates. Consequently, the diagnosis of many *DSM-IV* disorders depends on an additional generic criterion stating that the syndrome 'causes clinically significant distress or impairment in social, occupational, or other important areas of functioning', which has come to be known as the clinical significance criterion (CSC). The main conceptual argument against the CSC as the primary means for establishing diagnostic threshold is that given the same set of symptoms as indicators of underlying disturbance, individuals show varying degrees of distress or impairment due to contextual influences that are not indicators of underlying disturbance. For example, a child with symptoms of

attention deficit in a highly structured and supportive home and school environment may show much less distress or impairment than a child with the same symptoms in an unstructured or chaotic environment. Furthermore, as we saw earlier, for many disorders diagnostic thresholds do not signal a qualitative increase in functional impairment.

Furthermore, there are limitations and problems associated with the CSC when embedded within the diagnostic criteria for specific disorders. First, it is very difficult to ascribe impairments to a specific mental disorder when multiple disorders are present. That is, it is difficult to portion how much impairment is related to one disorder versus another disorder (von Korff, Andrews, & Devles, 2011). Second, by encouraging reliance on clinical significance to determine diagnostic threshold, there is less encouragement to refine the diagnostic criteria to optimally signal the core dysfunction. Some *DSM-IV* disorder criteria represent problematic behavioural (e.g. CD), cognitive (e.g. body dysmorphic disorder), or purely motoric (e.g. chronic motor tic disorder) syndromes without specifying the dysfunction of which the syndrome is the purported manifestation. The lack of linkage between diagnostic criteria and underlying dysfunction is believed to hamper attempts to identify the underlying disturbances in neurophysiology, cognition and emotion (see Narrow & Kuhl, 2011). Notably, the goal is not to revert to theory-driven etiological models, but rather to rely upon empirically derived disturbances that underlie symptom manifestation. Third, the concept of 'clinically significant' distress or impairment is vague, subjective (e.g. for how long does distress or impairment have to be shown, and once shown, is it a once-and-for-all criterion), and tautological (i.e. 'a disorder is defined by clinically significant distress or impairment, which is distress or impairment significant enough to be considered a disorder' (Narrow and Kuhl, 2011, p. 152; Spitzer & Wakefield, 1999). Fourth, the CSC can encourage false negatives in certain cases (e.g. Tourette's disorder, paraphilias, sexual disorders or substance dependence; Spitzer & Wakefield, 1999). In these cases, Spitzer and Wakefield argue that the requirement of the CSC excludes certain individuals from meeting diagnostic criteria even though they have severe, frequent or long lasting symptoms. For example, they note that the *DSM-IV* criteria for Tourette's disorder requires the presence of both distress and impairment, and yet there exists a large range in distress experienced by young children with tics, from extreme intolerance to denial of the tics most of the time, with the latter group not meeting the criteria for the disorder despite severe and frequent tics. Fifth, the CSC is inconsistent with general medicine, where distress or functional impairment is not usually required to make a diagnosis (Spitzer & Wakefield, 1999; Ustun & Kennedy, 2009). Sixth, the CSC is inconsistent with the ICD-10, and thus impedes attempts at

harmonising DSM-5 and ICD-11 (Narrow & Kuhl, 2011).

In contrast to the above arguments, proponents of the inclusion of impairment as a component of diagnosis might argue that the CSC is indeed a poorly defined construct, but this need not necessitate its elimination. Many symptom descriptions also show limited reliability and require clearer definition to improve them. In this same way, clearer definition of the CSC and use of behavioural descriptors and anchors should increase the agreement between raters in determining this criterion. With better operationalisation, the CSC may be more precisely related to each individual disorder among comorbid disorders, may be more directly linked with underlying disturbance, and would be less tautological. It might also be argued that mental disorders are not physical diseases and hence consistency of nosological systems between general medicine and mental health should not be a high priority. Of greatest significance is the argument that symptoms exist on a continuum and hence all individuals experience some symptoms of almost all disorders. Reliance on a consideration of functional impairment may be the best way to determine a threshold (Rapee & Coplan, 2010), even if that determination is necessarily correlated with symptom severity. Further, as described above, behaviours can dramatically change their meaning and impact in different contexts (recall the children of the Masai) and therefore the concept of 'disorder' cannot be context free. On the other hand, by maximising the role of contextual factors as determinants of diagnostic threshold, the CSC is discouraging the search for underlying disturbances.

For the previous reasons, the DSM-5 Impairment and Disability Assessment Study Group is recommending that impairment be viewed a consequence of disorder rather than a requisite feature of the disorder itself and that the CSC be removed from the diagnostic criteria (DSM-5 Impairment and Disability Assessment Study Group, 2011). Although this recommendation is unlikely to be fully incorporated into the version of DSM-5 that is published in 2013, it may be incorporated into later versions of the DSM nosology. As discussed previously, one of the most common objections to removing the CSC from the diagnosis of mental disorder is that the prevalence of the disorder would increase unreasonably. Indeed, prevalence rates have been shown to increase with exclusion of an impairment criterion (Canino et al., 2004; Merikangas et al., 2010; Romano et al., 2001). However, at least within adult populations, measures of impairment or distress that are independent of clinician judgment, such as presence versus absence of work days lost or patient self-ratings, do not differ between cases in which diagnoses were assigned with versus without the CSC (Andrews & Hobs, 2010; Breslau & Alvarado, 2007). That is, what the CSC actually measures is

unclear as it does not concord with objective measures of impairment. As already indicated, however, rather than remove the CSC from the definition of disorder, an alternative approach is to more clearly and operationally define the CSC.

Spitzer and Wakefield (1999) suggested that, in some cases, false positives could be more readily addressed by raising the 'severity' of the symptom criteria than by adding a CSC, and in other cases, the generic CSC is redundant with symptom criteria that already include impairment in functioning (e.g. ADHD). In this context, it is noteworthy that the DSM-5 Impairment and Disability Assessment Study Group is going further in recommending that DSM 'symptom' criteria that include impairment (e.g. destruction of property and violations of rules in CD) eventually be reworded to reflect more directly the underlying dysfunction, wherever possible. Again, this recommendation derives from the attempt to separate 'disorder' from 'consequences of the disorder', with the latter being strongly influenced by an individual's life context. For example, the frequency with which a child 'loses things necessary for tasks or activities (e.g. toys, school assignments, pencils, books, or tools)' (an attribute of ADHD) may be related to the level of structure in the home and/or school environment, as well as to a dysfunction in attentional mechanisms within the child. However, this represents a very significant change and may prove extremely difficult, as the criteria along these lines are constrained by how much we know about the underlying dysfunctions (in areas of neurophysiology, emotion, attention, memory, perception, thought, psychomotor, temperament, intellect, orientation and consciousness) for each disorder.

Furthermore, some symptoms appear to represent both core features of the underlying disturbance as well as disability, an example being phobic avoidance behaviour. One can view fear driven avoidance as a symptom of a dysregulated fear-circuitry system that often has a direct consequence upon participation in society (i.e. a disability). The amount of phobic avoidance is likely to correlate with the amount of disability (e.g. children with severe separation anxiety who avoid being alone may appear more disabled than children with specific phobias of animals who avoid only circumscribed situations). It may still be possible to disentangle avoidance symptoms from the consequences of those symptoms on disability, as two children with the same degree of phobic avoidance may have different degrees of distress or disability depending on surrounding environmental/contextual factors. For example, the child who avoids school because of separation anxiety but who receives home schooling is likely to be less disabled than a child with the same avoidance symptoms but who does not receive home schooling. However, full disentanglement of phobic avoidance and disability is likely to prove difficult, and this is likely just one example of the challenges involved in implementing

symptom criteria that, as much as possible, are independent of the consequences of the disorder.

This is not to say that the Impairment and Disability Assessment Study Group dismisses the concept of impairment, but rather views impairment (or disability) important to the description of the individual (vs. the disorder). Of course, measurement of impairment at the level of the individual was what was intended by the DSM Global Assessment of Functioning Scale. However, this scale conflates symptoms with functioning, and thus correlates with symptoms sometimes more than with independent measures of functioning (Narrow & Kuhl, 2011). Thus, the Impairment and Disability Assessment Study Group is proposing alternative measures of impairment for individuals. A self-report measure developed by the World Health Organization, the WHO Disability Assessment Schedule, has proven effective for measuring activity limitations and participant restrictions (i.e. disability) in adults, without conflation with symptoms. Similar measures are only beginning to be developed for children (e.g. Whiteside, 2009). von Korff et al. (2011) recommend that for adults, disability be measured by both self-report and clinician judgment, in accord with the principles established by the WHO. A major challenge in developing parallel measures for child and adolescent samples is to incorporate additional relevant sources of information such as parents and teachers in addition to incorporating the impact of the child's disorder on the parents and family.

## Summary

In summary, we have reviewed the constructs of impairment, distress, and quality of life, their assessment in young people, and their relationship to culture, development and gender. In addition, we

have described the impact of impairment upon prevalence rates. Given the consideration that is being given to separating the concepts of 'disorder' from 'disability' within future diagnostic systems, we have laid out the arguments for and against such a separation when diagnosing youths. On the one hand, there are a number of advantages to separating 'disorder' from 'disability', including the encouragement it would provide to developing symptom severity criteria that are tied to core dysfunctions. On the other hand, there are conceptual reasons to retain the concept of impairment as a means for determining thresholds, especially for dimensional symptom profiles. Furthermore, there are substantial challenges to fully implementing such a separation, as it assumes a level of knowledge about underlying core dysfunctions for each disorder that is beyond the current state of knowledge in many cases. At the very least, however, the current review highlights the need for further research into the assessment of impairment and its relationship to symptoms within youth samples.

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## Key points

- Recent conceptualisations of mental health are placing greater emphasis on the importance of functional impairment as a key consideration in the assessment and understanding of childhood mental disorders.
- Whether functional impairment should be conceptualised as a core component of a disorder or whether it is better conceptualised as a consequence of an underlying disorder, is a current point of debate.
- Psychometrically sound measures of functional impairment in children, taking into account domains of functioning, gender, culture and development, are needed.
- Functional impairment is a key motivator for service use and needs to become a core focus for interventions.

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