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# Assessing children's quality of life in health and social services: meeting challenges and adding value

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## Abstract

The measurement of children's quality of life has an important role to play in improving their experience of health and social services, and in promoting a child-centred approach to service provision. This article provides a rationale for both the development of robust quality of life measures specifically for children and also the use of these measures in assessing the effectiveness of treatments and policy changes. It highlights recent advances in the development of quality of life measures and provides examples of two instruments that have incorporated these steps to produce reliable and valid measures that are not only comprehensible to children of different age groups, but also meaningful to parents and health professionals. The challenge of matching statistically significant change in quality of life to changes of perceived importance to the individual is also discussed in the light of the advantages to be gained from the increased uptake within health and social care of quality of life measures for children.

## Key words

children; quality of life; health; measurement; health status

## Introduction

Quality of life (QoL) is defined by the World Health Organisation as 'An individual's perceptions of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns' (The WHOQOL Group, 1993). Although the need is widely acknowledged, the issue about whether it is possible to measure a child's quality of life in the context of health and social services, and if so how best to do this, has been hotly debated. In England, the National Service Framework (NSF) for Children (DoH, 2003) stated that a key rationale for investing in improving services was to help reduce costs later on, because earlier access to better child and adolescent mental health services 'can help to prevent the later

development of more complex problems and significantly improve quality of life' (p17). Services for disabled children and those with serious mental health problems were of particular concern: '[Children] require a comprehensive diagnosis and assessment to identify the social and physical barriers which may inhibit their access to the best possible quality of life' (2.10). Similarly, the Government's vision for children's services in England and Wales, Every Child Matters (DfES, 2003), and the subsequent Children Act 2004 established a responsibility for children's services agencies to not only ensure that at-risk children come to no harm but also to be proactive in ensuring that children have opportunities to improve their well-being. This would be manifested in the five outcomes of health, safety, economic well-being, enjoyment and achievement, and contribution

to society. Consequently there is an urgent requirement for robust methods of assessing children in relation to the spectrum of health and social needs and across the complete age range from early to late childhood. Without reliable and valid measurement instruments it will be difficult to assess progress against NSF and DFES targets. These issues are particularly prescient now, given the way that QoL and related concepts such as 'well-being' and 'happiness' are entering the public policy discourse and beginning to alter service provision (Jordan, 2006).

## Why measure quality of life in children?

QoL assessment was originally developed for use in health care settings. As such, one of its prime uses is for measuring QoL during the treatment of chronic disease. Measuring children's QoL has lagged behind that of adults, in part because there are far fewer chronic illness conditions in childhood (eg. lymphoma, juvenile rheumatoid arthritis, tuberous sclerosis) and therefore arguably less need for its use. However, the impact of chronic disease on a child's QoL may be much greater than for adults, for whom knowledge of the implications of having a chronic illness and expectations of disability and/or premature death replace normal expectations of a long, healthy life (Eiser, 1993). Furthermore, the QoL of children also influences the QoL of those on whom they depend and who must care for them. There is growing evidence that the QoL of carers is often poor due to raised levels of physical and mental health problems (Coen, 1999). In many situations there is little physical or mental respite from the demands of care, especially where resources are short, and so carers can become progressively debilitated themselves. Observers tend to rate the QoL of those for whom they care as significantly poorer than the individual themselves would rate it, and these perceptions can unduly increase the carer's distress with the caring process (Coen, 1999). In other cases pertinent to some conditions of childhood, notably profound deafness and learning disability (Summers *et al*, 2005), there may be difficulties in communicating about subjective QoL to others. Where measures are also designed for cross-cultural use in equivalent language versions, such as the WHOQOL (Bowden & Fox-Rushby, 2004), they can be invaluable in evaluating multinational clinical trials of interventions.

QoL measures have been used for many purposes in both health and social settings. In addition to being used to assess the effectiveness of treatments they have been used to compare the relative merits of

different treatments for the same condition, for example by taking account of patient preferences in weighing up the costs of side-effects versus potential benefits (eg. Fox-Rushby, 2002). This is as important to the care of children as it is to adults; indeed the US Food and Drugs Administration (FDA) now requires the inclusion of a good QoL assessment as a secondary outcome measure for *all* randomised controlled trials, including those that concern children (FDA, 2006). QoL measures can also be used to monitor the quality of services, for instance in relation to diabetes care, and the effects on well-being of changes to health and social care policies (Patrick & Erickson, 1993). Where measurement is of the highest psychometric standards, scales can be used at an individual level to improve doctor-patient communications and to help formulate a treatment plan (Patrick & Erickson, 1993). Similarly, in social care, QoL assessments have many uses: '*Health and social service authorities typically employ different information in planning their services... quality of life brings together information of many different types and offers a mutually acceptable common base of information which focuses on the total life circumstances of the individual*' (Oliver *et al*, 1996: 242).

QoL assessment can be used to enhance relationships with professionals through improving communications and acknowledgment of the individual's concerns, and by putting the actual needs derived from individual assessment at the very centre of service planning (eg. Greenhalgh *et al*, 2005). It can assist in determining the best course of action for a child, taking account of his or her own priorities in cases when no single available option is perfect. It also provides an avenue for opening up discussion with and engaging clients, for maintaining their interest and co-operation over time and monitoring whether services impact significantly on their life conditions (Oliver *et al*, 1996). For example, QoL has been shown to make a significant contribution to decision-making regarding the removal of at-risk children from their parental homes; this was based on social workers' judgements of their potential for future good QoL in the current home, compared with that if moved elsewhere (Davidson-Arad & Wozner, 2001).

The recent Adolescent Mental Health Initiative supported by the Nuffield Foundation (2005) indicates the acceptance of QoL as a multidimensional concept reflecting what has become standard practice in the QoL assessment of adults. The initiative sought input from professionals from a range of social and health fields in order to draw on the requisite expertise of the identified domains of QoL, including physical health, psychological state,

social relationships, level of independence and occasionally salient features of the environment and spiritual concerns (The WHOQOL Group, 1994). This confirms that QoL assessment may be best addressed and appreciated through a multidisciplinary approach. Consequently, a three year programme involving policy makers, researchers and professionals working with adolescents has been initiated to analyse the life experiences of UK adolescents, taking account of the influence of education, family and social factors where there is poorer mental health. More specifically, this research will examine recent QoL trends, compare QoL for this age group in the UK with other countries, and explore how the effects of societal changes relating to school, stress and parenting style impact on adolescent QoL.

But how can QoL be measured in children? Young children may be unable to understand abstract constructs like QoL and health where their cognitive development has not yet reached more advanced stages (Bibace & Walsh, 1979; Bullinger & Ravens-Sieberer, 1995). One issue, therefore, is whether it is possible to identify a definitive cluster of important and salient dimensions that make up QoL that can be more easily comprehended and discussed in concrete terms by younger children. A single index of QoL is arguably less clinically useful than a multidimensional profile because professionals need to know not just whether QoL has improved or deteriorated, but exactly which quality areas are worst affected – sleep, mobility, family relationships, and so on. In the absence of the detailed information that a multidimensional assessment provides, targeting a specific area for effective intervention is difficult and fraught with risks.

## How to measure quality of life in children

The departure point for this discussion is a World Health Organisation (WHO) meeting in 1993 that brought together experts from many countries with diverse health, medical and social science disciplines to summarise the important issues that challenge the successful measurement of QoL in children (World Health Organisation, 1993). In addition to inherent developmental problems of communicating appropriately with children about their health and well-being in the language that they comprehend (Eiser, 1997), it was also important to design measures that would be sufficiently flexible to take a child-centred perspective. This was because the few measures available at that time for assessing children's health tended to seek perspectives of

'significant others' and/or health professionals, to the exclusion of client-centred methods.

However, there has been a significant shift in recent years in the health field towards asking the patient/client about their QoL, using patient-reported outcome measures – also known as 'PROMS' (FDA, 2006) – together with similar moves in social care in recognition of the importance of the child's voice (eg. James & Prout, 1990; DoH, 2003). This change in orientation complements the UK government's recent proposals for children's services, the first principle of which is that all policies and provision should be centred on the child's needs. So in assessing the QoL of children for the purpose of evaluating services, it is paramount that the child's perspective is taken into account.

Similarly the WHO has taken a person-centred perspective in its definition of QoL. Conventionally, QoL assessment in health care involved counting or rating symptoms or problems, and was driven by the problem-centred demands of the clinic. However, this approach has not been entirely successful, not least as it contradicts day-to-day observations made by the helping professions. Doctors, social workers and community nurses are frequently consulted by patients who have many symptoms or problems yet report a relatively good QoL; conversely those with very few symptoms often report their QoL to be poor; an example could be psoriasis (Skevington *et al*, 2006). Therefore counting symptoms or measuring problem intensity has only very limited value in QoL assessment for adults and children alike, and new approaches are needed. Furthermore, when important QoL topics are phrased in a positive rather than problem-centred light, a different and more holistic perspective of that person's QoL emerges, for example asking them to rate their level of independence rather than dependence (The WHOQOL Group, 1994). In practice, adults report that completing a questionnaire that provides a more positive orientation is a less depressing experience for them because it presents a more balanced view of life – positive with negative. This may be true for children too, but until recently self-completion measures for children have largely been framed in a problem-centred way (eg. Pediatric Quality of Life Inventory, Varni *et al*, 1999). Where appropriate and feasible, some of the newer instruments for children detailed below such as the C-QOL (Jirojanakul *et al*, 2000) and the KIDSCREEN (Ravens-Sieberer *et al*, 2005), have adopted these principles and adapted approaches derived from thinking about the need for subjective assessments of QoL in adult health; these two were inspired by the WHOQoL.

At a broader community or population level, the measurement of QoL has commonly been estimated through a range of objective indicators, from morbidity and mortality statistics and levels of environmental pollution, through to proximity of parks and playgrounds. For example, outcomes used to assess the success of UK local governance in achieving sustainability targets include unemployment levels, election turnout and the number of new businesses established in an area (Audit Commission, 2002). While such indices may have advantages in allowing retrospective or international comparisons, they provide very limited insights into the actual experience of people living in those environments. For instance, is it really a true indication that a child's QoL is better if they are enrolled in more after school clubs (one indicator), regardless of why they attend or whether they enjoy them? Even at a population level, subjective QoL assessment is possible and has already been incorporated into several national surveys, albeit in addition to objective indices. Thus, the Families and Children's Study (Lyon *et al*, 2005) sampled over 5000 children aged 11–15 and their parents, incorporating children's subjective evaluations of family and school life, their appearance, and 'life as a whole'. Similarly, a number of subjective items such as people's perceptions of community safety and their perceived ability to influence local decision-making have now been included in evaluations of local governance targets (Audit Commission, 2005). The results of these studies provide invaluable data for policy-making in education, public health and social care.

### Specific concerns about quality of life measurement for children

The World Health Organisation (1993) expert group recognised that there would be some specific issues pertaining to the measurement of children's QoL that were not relevant to adults and that would need to be addressed. First, the age range was a particular concern and so if the measure was multidimensional, cognitive, psychological and physical dimensions in particular would need to be adjusted to that age group. Second, pre-morbid functional and cognitive abilities cannot be established in very young children and, because of this, may necessarily curtail the length of valuable longitudinal studies. Third, it was acknowledged that any subjective QoL assessment should be obtained in association with other ostensibly objective variables, like physician observations. Proxy judgments by carers and professionals would be needed where children were

too young, ill or seriously disabled physically or psychologically to make their own self-reports. However the age at which proxy judgments could be dispensed with was unknown, and today this is still debatable and an important area for further investigation. Recently, assessments of family QoL have appeared in the literature by examining satisfaction with life in families where the impact of a child's intellectual disability is a concern (Summers *et al*, 2005). That said, if QoL is inherently about the personal meanings of different life experiences – as indicated by the WHO definition – then it is questionable as to whether, like proxy assessment, the results from group assessments are truly reliable. Fourth, there were some important dimensions of particular relevance to a child's QoL that were not necessarily considered important by adults, such as teasing and bullying, but which would need to be incorporated into any assessment to cover the full QoL concept for children. A large number of these were identified by the expert group as being in the social domain, notably parental relations, valuable adults and pets. At a physical level, body image – including hair distribution and body size – was mentioned, as were environmental aspects like school food, chores, space and play. Fifth, there was consensus that an international measure that could establish core universal constructs that make up QoL for children globally would have useful practice and research applications in improving children's health worldwide. It was also recognised that these issues would need to be tested and confirmed by the users themselves during development, using carefully applied child-friendly interviewing techniques. Have these observations been acted upon?

### The development and testing of QoL measures

Since that time, several well-accepted measures have been developed to assess children's QoL. For example, the General Child Health Questionnaire (GCHQ) (Collier, 1997) uses an innovative, child-friendly response format, the ComQOL (Cummins, 1997) combines objective with subjective factors and the KINDL (Ravens-Sieberer *et al*, 1999) provides a pan-European QoL measure comprising a generic core module with additional disease-specific components. What are the strengths and weaknesses of such measures, and to what extent are they useful in practice settings in children's services?

A comprehensive report on health-related QoL measures conducted for the NHS Health Technology Assessment Programme (Eiser & Morse, 2001) made



recommendations regarding the value of currently available instruments for different purposes and identified further research needs; this provides a foundation to this discussion. The report identified 19 generic health-related measures designed to assess children's QoL and examined their reliability, validity and application, together with their orientation (eg. positive/negative, functional deficit vs. positive health) and practical issues such as completion time. Common barriers to the use of such measures outside academic settings were a distrust of the reliability and validity of scores, concerns about time burden on staff and difficulties with interpreting statistical differences. However, the authors argued that if practitioners working with children and adolescents on a daily basis *could* be convinced of the utility of QoL measures, these scales have the potential to enhance comparisons of research trial outcomes, to evaluate interventions, allocate resources and assess long-term treatment outcomes. Key recommendations for the development of high-quality measures were that: procedures for producing an item pool for a measure should be systematic and clear; the psychometric properties of the measure itself and criteria for item inclusion should be robust and clear; measures must be developed closely with clinicians to improve their relevance to clinical need and meet quality standards; and families should be involved in the development of measures to help ensure that children are not overburdened. They also highlighted the need for developmentally sensitive age-appropriate sections, and recommended that assessments developed to measure children's QoL should take account of a child's understanding of illness and emotion and their ability to complete scales (with the facility for child and proxy reports). Measures should also include a generic core of items that can be used for all diseases and conditions, so precluding the necessity of having to select a specific scale appropriate to the disease of each patient that reduces the possibilities of comparing across conditions. Instead, the availability of disease-specific modules that could be tacked on to the generic core for use with specific populations would provide greater flexibility and comparability to satisfy audit purposes. While based within health practice, these recommendations are equally applicable to other children's services settings, including social care and education.

Two research groups have since explored these issues while incorporating an international focus. In Thailand, Jirojanakul and Skevington (2000) investigated whether the cross-culturally agreed multidimensional concept of QoL published by the WHOQOL Group and confirmed by adults in 15

countries worldwide, including Thailand, would be applicable to children. Adapted from the WHOQOL methodology (see Skevington, 2004; Skevington *et al.*, 2004), children aged five to eight years were interviewed about their QoL using pictorial methods and stories, and focus groups were conducted with carers. Directly as a result of this child-centred approach, some adult concepts such as sex life were removed, and a school-oriented perspective was introduced. More importantly, however, it provided an appropriate, holistic concept for children. Furthermore, two new dimensions were recommended for inclusion but articulated in child-friendly terms: the right to speak out and be heard, and the right to have an identity and citizenship. Careful checks were made of children's understanding of terms, and with regard to the validity and consistency of answers. New, more visual, five-point response scales were constructed using 'smiley faces' to evaluate levels of satisfaction (eg. with the ability to take care of themselves), 'fingers' to represent intensity and capacity (eg. to help parents with the housework) and 'clocks' to demonstrate frequency (eg. of being sad). A survey of children and mothers that tested separate child and parent versions of the resulting C-QOL instrument showed good internal consistency (.84-.86), and good test-retest reliability (.90-.91) for both forms, and enabled suitable items to be selected so that the measure could be shortened (Jirojanakul & Skevington, 2000). The results confirmed that with modification, the WHOQOL framework was largely appropriate and acceptable to children, and its 25 dimensions of QOL were important to both user constituencies (children and parents). More significantly, it showed that even at age five to eight years, children can be reliable reporters of their own QoL if appropriate tools and procedures are piloted and used to gather this information. Parents, by contrast, are not always accurate assessors of their child's subjective QoL, especially in the psychological domain. This is because so many aspects of children's QoL are not open to inspection or observation. For this reason proxy information should only be used where special conditions require it.

In a subsequent study, Jirojanakul and colleagues (2003) examined objective and material features of a young child's QoL, such as mean hours spent travelling to school daily, time spent studying and family income, to see if they could predict a child's subjective QoL, as measured by the C-QOL. Survey information obtained from 498 children aged five to eight years and living in urban locations, especially building sites in Bangkok Metropolitan, showed that

father's income and his educational level best explained a child's QoL. The type of school attended, the mode of transport to school, and time spent in extra study also made important contributions. A curvilinear relationship between pay and QoL demonstrated that by increasing pay to the lowest paid fathers (Bahts/month), this would have the greatest impact on directly improving a child's QoL (Jirojanakul *et al*, 2003). Thus, assessing the impact that different objective factors of children's lives can have on their subjective QoL can provide evidence on which to base recommendations for change in welfare and occupational policies, highlighting specific areas with the greatest potential to improve children's QoL.

The European Union has funded two projects called KIDSCREEN and DISABKIDS that provide good examples of how the development of QoL measures reflecting the elements of good practice discussed so far have been put into action on a larger scale, and with a broad age range (Herdman *et al*, 2002; Petersen *et al*, 2005; Ravens-Sieberer *et al*, 2005). These partner projects were set up in 2001 to develop transferable, standard QoL measures for use with both healthy and chronically ill children aged 8–18 years in Europe. Both instruments were developed through a participatory approach involving professionals, children and their families in all participating countries. The DISABKIDS questionnaire contains a generic core module supplemented by condition-specific modules for a number of different chronic childhood illnesses, alongside parent proxy forms. Particular attention has been given to formatting self-report versions to reduce the response burden for chronically ill or disabled children. Although as short as possible, the questionnaire contains 37 items to address six domains (independence, emotion, social inclusion, social exclusion, limitation, and treatment), recorded on a five-point Likert scale. Furthermore, a version using 'smiley faces' rather than verbal anchors is available for young children and those with communication difficulties.

The KIDSCREEN project extends the scope of existing QoL measures beyond health, and allows detailed assessment of children who are considered to be 'at-risk', in relation to their subjective health and well-being. Designed for use in health and social services, it is intended to help identify cases for which early intervention to promote health and prevent harm may be warranted. It does this through earmarking QoL domains that may be associated with risk behaviours that are affected by factors beyond the individual's control, but which could be influenced through social/health policy and interventions. Thus,

KIDSCREEN is useful in healthy communities whether from a social services perspective or that of preventive health services, in recognition that the onset of problem lifestyle behaviours in adolescence, such as risky drinking, drug taking and sexual practices may be as much of a threat to health and well-being in this age group as diseases themselves. QoL is reported across multiple dimensions rather than purely as a single index', and unlike traditional measures focusing on ill-health, has a positive orientation (eg. 'Have you felt full of energy?').

Due to their recent development, there are few published reports of the DISABKIDS and KIDSCREEN measures beyond the initial validation trials. Internal consistency reliability (Cronbach's alpha) from samples of over 20,000 children was shown to be acceptable to good (KIDSCREEN, .77–.89; DISABKIDS, .71–.90) (Ravens-Sieberer *et al*, 2005). The authors report a high demand for the instruments in different countries, for use on projects varying from basic academic research to the evaluation of interventions, and indicating a very real need for such measures. A short (10 item) version of KIDSCREEN is now incorporated in the WHO Health-Behaviour in School-aged Children survey (HBSC) taking place in 41 countries, highlighting age transitions in health, and examining gender differences in 11, 13 and 15 year olds (HSBC, 2006).

## Quality of life measures in action

Notwithstanding their obvious potential for research and practice as indicated in previous sections of this article, little research exists documenting how children's QoL measures have been translated into practice with children. However, as many of the same professionals and systems are involved in both research and the treatment of children as they are for adults, some conclusions can be extrapolated from the evaluation of the impact of QoL assessment in adults. A primary obstacle has been the reluctance to adopt such measures by frontline staff, whether through scepticism regarding their validity and utility or more practical concerns; key problems linked to routine implementation into social and health care practice include time pressure, lack of ownership by frontline staff and little senior support (Oliver *et al*, 1996). The inclusion of QoL as an outcome measure in clinical trials has increased in recent years, leading to recommendations such as changes to first-line drug choice or drug combinations (Efficace *et al*, 2003), but relevant findings and recommendations from research are still not automatically implemented. This reflects reports that the importance of QoL in relation

to other treatment-related outcomes is often ranked very low by clinicians, with many believing that it is unnecessary, particularly beyond palliative care (Morris *et al*, 1998). Furthermore, most QoL measures commonly lack a standard means of classifying cases for comparison ie. patients in acute or chronic treatment versus those discharged, or children in care versus children living with parents.

The second observation is that, despite these difficulties, at wider levels such as policy development and treatment protocols QoL has proved a useful additional outcome measure to assist choices between effective treatment options. For example, one review of the utility of QoL as an outcome measure in clinical trials of cancer treatments found that health-related QoL indicators could discriminate between treatment regimens (namely, courses of therapy) in 74% of trials, whereas traditional clinical outcome measures could only differentiate in 46% of cases (Efficace *et al*, 2003). In other words, QoL scores provided a means of differentiating between an additional 28% of treatment options for which no difference was apparent from using traditional medical indicators. What is more, such distinctions lie along an axis that is extremely meaningful for people suffering from chronic illness. This powerful evidence shows that if QoL indicators were to be routinely adopted into practice by social and health care professionals, they would add a great deal of potentially useful information. The challenge, therefore, lies in communicating to practitioners and decision-makers the ways in which these indicators can be useful, and in presenting the results in an accessible and meaningful fashion.

This leads to a third comment, which concerns the potential advantages of QoL measures in the context of existing approaches to assessment and evaluation in children's services. Many applications and examples of their potential value are seen in palliative care within the health service, providing benefits in prevention, and in early intervention work in social care and education settings. In England the Common Assessment Framework (CAF) that emerged from Every Child Matters is a standardised approach to conducting an assessment of a child's additional needs and deciding how those needs should be met (see DfES, 2006). Now used by practitioners nationwide, it recognises the need to attend to multiple dimensions of a child's life and incorporates the assessment of subjective as well as objective factors (eg. taking account of a child's opportunities to pursue their aspirations, as well as paying attention to their physical safety). The form requires

practitioner judgements (ie. proxy assessments) across a range of 14 domains that resemble those used in many QoL measures, ranging from a child's physical, emotional, social and behavioural development to the adequacy of parental care and guidance and the nature of broader family functioning and environment. Based on the limited contact available with that child, completing such a form may be a daunting prospect even for experienced practitioners. In view of the work in health reported earlier in this article that has identified areas of disparity between proxy and self-reported QoL, a useful next step might be to supplement these proxy measures, where feasible, with child self-reports. As well as indicating how far observed inadequacies in care translate into diminished QoL, this could also highlight other areas of concern to the child that may not have been identified, or help to establish the child's priorities among the multiple problems to be tackled. The use of a standard, brief and user-friendly measure throughout social services, with established psychometric properties (reliability and validity) would also lend itself readily to aggregation of results for planning purposes. It is encouraging that the CAF clearly requires a multidimensional assessment of the child's subjective well-being to be carried out at the point when decisions on action are made, but it remains to be seen how much weight these carry compared with traditional outcome measures (an evaluation is forthcoming).

The fourth point relates to recent debate in health-related QoL research about objective and subjective perspectives, in particular the need to establish what degree of change on an outcome measure (and following an intervention) constitutes a personally meaningful or a clinically significant change. The boundary of personally meaningful change can be identified by patients and is expressed as a minimally important difference (MID) in their experience. The MID is defined as the smallest difference in score that is perceived to be beneficial (Juniper, 1998; Juniper *et al*, 1994). Thus, rather than judging changes either in terms of statistics or biological markers, change is judged to have occurred if a person notices it, and values that degree of change. Outside health care, parallels can be drawn with 'practical significance', relating to the degree of change in a problematic area of a child's life that the child or a relevant adult such as a teacher would consider notable and worthwhile. Clinically significant change, by contrast, is more closely aligned to changes due to treatment and can be defined as '*a difference score that is large enough to have an implication for the patient's treatment or care regimen*' (Wyrwich *et al*, 2005). For example,



what degree of improvement in sleep, or reduction in pain, would a patient consider sufficient to make their life noticeably better/more bearable, or would lead to their clinician adjusting the type or dose of treatment. International guidelines and recommendations for conducting clinical trials and reporting their results have recently been proposed to assist in evaluating clinical significance (Wyrwich *et al*, 2005). Through reporting levels of meaningful, practical or clinical change rather than raw change scores, results can be presented in a similar fashion to other objective clinical indicators with which health professionals are familiar, such as the 'number needed to treat' analysis (ie. the number of patients who need to be treated to prevent one adverse outcome). Using one of these methods in presenting results increases the likelihood that QoL changes will be understood by others and that they will be regarded as meaningful and subsequently taken into account in decision-making. Careful piloting and development of child-centred methods is needed before meaningful and reliable reports of clinical, practical or meaningful change can be established within this age range, and this is a challenging frontier for applied QoL research.

## Conclusions

Multidimensional QoL measures can contribute useful information to a variety of health and social care issues, yet although their use is increasing, an appreciation of their full potential is still somewhat limited. Recent advances in research on children's QoL have led to the development and standardisation of a number of psychometrically sound self-report

instruments developed with input from the children themselves. These instruments have been shown to be of high quality in terms of reliability and validity, although in some cases their responsiveness to clinical change is still being investigated; that is, it is still to be established how sensitive they are to acute or more long-term changes in a child's circumstances.

Once language is established and the earliest stages of conceptual development transcended, even very young children have been found to be able to report on their own QoL with considerable accuracy when provided with developmentally appropriate self-report techniques. The existence of robust instruments should enable QoL to be fully incorporated in current moves towards a more child-centred approach to the provision of children's services. It should provide greater confidence for practitioners and researchers alike with regard to the accuracy of the information they generate, and this could be used to promote better decision-making at the individual child and planning levels and also contribute to the robust evaluation of new interventions. In addition, this work feeds into the current agenda concerning children's rights to have a say in their care and to be active agents in determining their own future.

Further work remains in charting the degree of change that constitutes clinical or practical (as well as statistical) significance, and in promoting the inclusion of QoL measures into the relevant treatment and research processes where they have meaningful information to add. A final major challenge is to design innovative ways to assess subjective QoL in pre-lingual and early lingual groups, from birth to four years of age.

## Summary of policy and practice implications

- Quality of life measurement provides a broad perspective on the impact of health and social services for children, and is pivotal to a child-centred approach to service provision.
- Children's quality of life measures can contribute meaningfully to the assessment of individual treatment, the outcome of clinical trials (or evaluation of services) and the impact of policies more broadly in health and social care for children.
- With built-in precautions and use of new methods, children as young as five are able to report reliably on their own quality of life, providing information about different areas of subjective well-being that are not immediately visible to proxy reporters, such as parents or practitioners.
- Although not widely appreciated, robust measures of children's quality of life are readily available for use in practice and research.

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## Endnotes

- <sup>1</sup> The KIDSCREEN consists of ten dimensions; physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance, and financial resources, scored on a five-point Likert scale.