

A qualitative study of the health-related quality of life of disabled children

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This qualitative study investigated what disabled children thought most important in their lives and examined how well their priorities are represented in **KIDSCREEN**, a generic health-related quality of life (HRQoL) instrument. Participants were a subgroup of families who had previously taken part in a study of quality of life and participation in children with cerebral palsy (CP) using **KIDSCREEN**. This subgroup was sampled purposively, using children's scores on **KIDSCREEN** and demographic characteristics. Twenty-eight children (15 males, 13 females; age range 8y 3mo–13y 5mo) and 35 parents were interviewed. Ten children were at Gross Motor Function Classification System Level I, 15 were at Levels II or III, and three were at Levels IV or V. Eleven children had unilateral spastic CP, 16 had bilateral spastic CP, and one child had dyskinetic CP. Interviews were audio-recorded and transcribed verbatim. The analysis was based on the constant comparative method and focused largely on the children's data, though the parent data were drawn upon to illuminate the children's data. Four overarching areas of HRQoL were identified: social relationships; home and school environment; self and body; and recreational activities and resources. These generally mapped well to the dimensions and items in **KIDSCREEN**. The precedence children gave to environmental, social, interpersonal, health, and functional concerns corresponded well with the balance of these items in **KIDSCREEN**. However, children had some specific priority areas that were not represented in **KIDSCREEN**. These included: relationships with family members other than parents; inclusion and fairness; home life and neighbourhood; pain and discomfort; environmental accommodation of needs; and recreational resources other than finances and time. We recommend that further consideration be given to inclusion of these areas in the assessment of HRQoL of disabled children.

We report on a qualitative interview study investigating the areas that disabled children think are most important to their quality of life. The aim was to examine how well children's priorities are represented in **KIDSCREEN**,^{1,2} a generic self-report health-related quality of life (HRQoL) instrument for children. The study was also driven by several more general concerns. First, children's opinions have been largely absent in the development of HRQoL instruments.^{3,4} Accounts of instrument development tend to draw on the perspectives of experts or parents⁵ but it cannot be assumed that these match the priorities of the disabled children.⁶ Second, even where children's views have been sought during the development of instruments, it is uncertain how far their perspectives persist through the processes used to ensure valid dimension structure and scaling properties. Third, reports of HRQoL instrument development have mostly neglected to make explicit the values and assumptions they embody^{7,8} or how the instruments balance function and health dimensions against environmental, social, and interpersonal dimensions. As HRQoL is increasingly valued as a key outcome in studies designed to influence service and policy development, it is important that these issues are examined in relation to disabled children.^{9,10}

KIDSCREEN aims to measure children's own experiences of their health and well-being across a broad range of dimensions, including social, emotional, and cognitive aspects of life, as well as physical or functional aspects (Table 1).^{1,2} As a generic instrument it seeks to be suitable for the general population of children and is distinct from condition-specific instruments that assess HRQoL in children with particular illnesses or conditions.⁶ A key feature of **KIDSCREEN** is that children's views, including those of children with chronic illnesses, were sought to inform the development of the instrument.⁴ However, empirical investigation of how well it maps onto the perspectives of disabled children is necessary¹¹ to assess how far it reflects their priorities.

Method

Ethical approval was granted by a UK Multi-centre Research Ethics Committee. Families were purposively sampled from the children in the north of England (NoE) arm of the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE). SPARCLE is a European quantitative survey of children with cerebral palsy (CP); details of the methods and sample are available.^{12,13} Purposive sampling is widely used in qualitative research, where methods such as in-depth interviews preclude large samples, and where random samples may result in failure to include participants with potentially important characteristics.¹⁴ Children's total scores^a and dimension score profiles generated by **KIDSCREEN**,^b and child and family demographic characteristics, were used to select the subset for the qualitative interviews. This subset included: (1) children from waged and non-waged households; (2) those with HRQoL reports across the range of total scores observed in the NoE arm of SPARCLE; and (3) for each dimension, at least one

^aThe designers of **KIDSCREEN** do not recommend the totalling of scores as this can hide important differences between children on the different 'dimensions' of the questionnaire. For this reason, the children's dimension scores were also considered when conducting the sampling and analysis.

^bThe version of **KIDSCREEN** used in SPARCLE, **KIDSCREEN-52**, was validated for healthy and chronically ill children aged 8 to 18 years and had 52 items.

child with the minimum score and at least one child with the maximum score.

Most interviews took place in the family's home in privacy from other family members, with special attention to enabling the active participation of the children.^{15,16} Separate topic guides were used for children and parents. The children's guide included prompts about interests and activities, relationships, feelings, and school; the parents' guide covered similar topics. The interviews lasted between 45 and 90 minutes, and with the exception of one child whose interview was recorded in detailed notes, were audio-recorded and transcribed verbatim. All participants provided informed consent or assent for the study.

Analysis was guided by the constant comparative method¹⁷ and by writings on quality in qualitative research.^{14,18,19} Team members worked in pairs on the parent and child data sets to develop open codes, followed by thematic categories. These were organized into separate coding frameworks for the child and parent data, which the team tested and refined by: (1) periodic discussion; (2) coding transcripts that had not previously been open coded; and (3) producing detailed reports of data coding in NVivo.²⁰ All the coded child data were scrutinized to extract the key components of children's accounts of HRQoL, and identify from these their HRQoL priorities. These priorities were compared with the dimensions and items in KIDSCREEN. Though the focus of the analysis was on the children's data, the coded parent data were then drawn upon to illuminate the conceptualization of the children's data.

Results

Of the 116 children who participated in the NoE arm of SPARCLE, 30% had impairments that prevented them self-reporting on KIDSCREEN. KIDSCREEN scores were available for 81 (70%) children. Of these, 67 (86%) families agreed to further contact, whereas three families could not be approached because of the timing of ethical approval. Thirty-four families were selected purposively from this pool and 29 families participated (28 children and 35 parents). The age range of children at interview was 8 years 3 months to 13 years 5 months (mean 10y 9mo [SD 1y 6mo]). Table II summarizes impairment and basic demographic characteristics of the participating children.

The qualitative analysis generated four overarching themes:

Table I: Summary of KIDSCREEN^{1,2} dimensions

Physical well-being: focuses on physical activity, energy, and fitness
Psychological well-being: focuses on positive emotions and satisfaction with life
Moods and emotions: focuses on negative emotions
Self-perception: perceptions of self, appearance, and body-image
Autonomy: perceptions of freedom of choice and self-determination
Parent relations and home-life: perceptions of interactions and relationships with parents and the socio-emotional atmosphere at home
Social support and peers: perceptions of relationships with friends and peers and the support available from them
School environment: perceptions of academic abilities and feelings about school and teachers
Social acceptance: perceptions of rejection by peers
Financial resources: perceptions of adequacy of financial resources relative to peers

social relationships; home and school environments; self and body; and recreational activities and resources. For each of

Table II: Impairment and demographic characteristics of participating children (*n*=28)

<i>Classification</i>	<i>n</i>	<i>%</i>
Gross Motor Function Classification System level ²²		
I Walks and climbs stairs, without limitation	10	36
II Walks with limitations	6	21
III Walks with assistive devices	9	32
IV Unable to walk, moving about is limited	2	7
V Unable to walk, moving about severely limited	1	4
Bimanual Fine Motor Function level ²³		
I Without limitation	12	43
II/III Both hands limited in fine skills or needs help with tasks	14	50
IV/V Needs help and adapted equipment or total human assistance	2	7
Communication		
Normal	21	75
Difficulty but uses speech	3	11
Uses non-speech for formal communication	4	14
No formal communication	0	0
Intellectual impairment		
None or mild	22	79
Moderate or severe	6	21
Cerebral palsy subtype		
Unilateral spastic	11	39
Bilateral spastic	16	57
Dyskinetic	1	4
Schooling		
Mainstream	21	75
Split between mainstream and special unit	0	0
Special unit in mainstream	1	4
Special school	6	21
Area of domicile		
City	1	4
Town or suburbs	22	79
Village or countryside	5	18
Sex		
Male	15	54
Female	13	46
Age, y		
8	4	14
9	7	25
10	5	18
11	7	25
12	3	11
13	2	7
Family structure		
Two parents	23	82
Lone parent	5	18
Family employment		
Waged ^a	21	75
Non-waged	7	25
Maternal education		
Intermediate qualification/university degree	7	25
Lowest formal qualification or none	21	75
Paternal education (<i>n</i> =23)		
Intermediate qualification/university degree	7	30
Lowest formal qualification or none	16	70

^aAt least one resident parent in regular full- or part-time paid employment.

these we summarize the children's accounts, presenting illustrative verbatim quotations (see Table III) and offer a comparison with the KIDSCREEN dimensions and items (the latter are listed in Table I). To safeguard anonymity, each quotation is labelled with the child's age range only and a unique participant identity number.

SOCIAL RELATIONSHIPS: FAMILY MEMBERS

Children spoke warmly about their relationships with their parents and greatly valued their affection, companionship, and support. This was illustrated by the frequency with which parents featured in children's accounts of a 'perfect day' or as confidantes during difficult times. Children also

Table III: Verbatim quotations from children and explanation of transcription symbols

<p>Social relationships: family members C: ((sibling name))'s the best and he plays with me and stuff ((...)) but he can sometimes get ratty so we hurt each other and play fight which annoys my mum ... (laughs), but we enjoy it, it's fun. <i>Female aged 11–13 (ID 233)</i></p>	<p>C: ((signals 'no')) I: No, would you like to see ((friend's name)) in the holidays? C: ((laughs and moves excitedly in his chair)) yeah, yeah ((laughs)). <i>Male aged 8–10 (ID 527)</i></p>
<p>I: I'd like to know what makes you happy? C: Er, (3s) weekends and all that, to be with my mam ((...)) and to be with my dad on a Sunday. <i>Male aged 8–10 (ID 226)</i></p> <p>I: What is it that's good about mam? C: Um, she's nice and um, I love her and she's just really nice and helps us with things and um, she's just really nice to me (giggles). <i>Female aged 8–10 (ID 170)</i></p>	<p>Self and body I: I heard that you fell down the stairs one day C: ((sounding quite proud)) I fell down the stairs twice. <i>Male aged 8–10 (ID 67)</i></p> <p>I: 'Cos you have got crutches now ... what are they like? C: Um exciting, 'cos, when I first got them, I kept, ((laughs)) I kept collapsing but now the, two weeks later I was racing around in them. <i>Female aged 8–10 (ID 43)</i></p>
<p>Social relationships: friends and peers C: He threatens me you know, he threatens me every single day (5s) he says 'I'm gonna kill you' I: And how does that make you feel? C: I'm gonna punch him tomorrow, that's why, that's what I'm gonna do ((...)) It's really annoying. <i>Male aged 8–10 (ID 67)</i></p> <p>I: Did it upset you, did it make you feel sad? C: No, I did not feel sad, it made us feel angry, I just felt like going over and giving them a good whack ((...)) because calling me 'spacca' is a really offensive name because of the condition what I've got. <i>Male aged 11–13 (ID 74)</i></p>	<p>I: Mm, what's bad about wearing splints then, what's it like? C: It just drives us insane ... They sometimes hurt, it depends if I've worn them out or not 'cos um, they put foam on them, extra layers and sometimes they wear out, the foam ((...)) So that's the only time it hurts ((...)) It's just I have to wear them every single day while everyone else is either wearing trainers or football boots. <i>Male aged 11–13 (ID 39)</i></p> <p>C: Gets on your nerves, it gets on your nerves having them ((sticks)) anyway ... It's annoying the fact that I can't be like any other, I can't be like my brother and sister, instead of just, doing things that I want to do. <i>Female aged 8–10 (ID 40)</i></p>
<p>School environment I: What's it ((school)) like? C: Good ((...)) yeah 'cos I have automatic doors. <i>Male aged 8–10 (ID 418)</i></p> <p>I: Are you looking forward to going to the bigger school or would you rather stay [where you are] C: Rather] stay where I am 'cos there's staircases all the way up and that ((...)) when people are coming down, they don't care, they just wanna get to the next lesson ((...)) They rush, and there's actually a girl my mum knows and she's been pushed down the stairs by a bully. <i>Female aged 11–13 (ID 233)</i></p>	<p>Recreational activities and resources C: Probably stay in bed till about one o'clock ... And then, get up, watch the telly ... Go and call for me mates and see if they want to go out or come round my house or go in theirs ((...)) And then I'd probably go on me Playstation ... And then have me tea and then go to bed again ((...)) Yeah but a perfect day would only happen like once in a year, if it would ever happened, which it hasn't really, 'cos I'm, but that's the dream day, if I could do anything I wanted, that's what I would do for one day. <i>Male aged 11–13 (ID 74)</i></p>
<p>I: Is there anything good about school? C: ((signals 'yes')) ... (10s) ((typing 'F' on dyno-vox keyboard)) I: Is it okay for me to guess? Words? C: ((signals 'yes')) I: Are friends what is good about school? Is that what you mean there with 'F' for friends? C: ((signals 'yes')) <i>Male aged 8–10 (ID 416)</i></p>	<p>I: Is Cubs as horrible as school? C: Er, it's worse ... ((shouting)) I just sit there, go round in the circle, do the grand howl, which is quite boring ... And we just sit and Miss, all Miss says is ((shouting)) 'BAH BAH BAH Sit Down!', it's a horrible place ((...)) And no fun things ever happen ... Not one ... Miss always tells us what to do. <i>Male aged 8–10 (ID 37)</i></p>
<p>Home environment I: OK tell me what's good about being at home? C: 'Cos I can go and play on my Playstation any time I want. <i>Female aged 8–10 (ID 170)</i></p>	<p>I: OK, and tell me about this Gym Club then, why did you stop going to that? C: Because um, I thought that I couldn't, 'cos I couldn't do um, (2s) cartwheels and I just couldn't do it so I just quit ((...)) I felt really like, sad, 'cos I wanted to do it but I couldn't. <i>Female aged 8–10 (ID 170)</i></p>
<p>I: Do you like it when you're off school? C: Yeah, it's fun ... no working and no telling off ((...)) I can do anything I want. <i>Female aged 8–10 (ID 225)</i></p> <p>I: Do you see ((friend's name)) out of school? C: ((signals 'no')) I: No? Do you ever see ((friend's name)) at this house?</p>	<p>Transcription symbols [] Overlapping speech (xs) Notable pauses WORD Loud speech, relative to the surrounding speech () Indicates transcriber's inability to hear what was said (word) Probable hearings of unclear speech (()) Author's descriptions rather than actual transcriptions ((...)) Small amount of speech has been removed by author for brevity Speech trailing off</p>

placed considerable emphasis on their relationships with siblings and grandparents and the companionship, stimulation, and support these individuals provided.

Many elements of children's accounts of family relationships were directly represented in items within the KIDSCREEN dimension 'Parent relations and home life'. This includes perceptions of parental affection, fairness, understanding, companionship, and the role of parents as confidants. However, there is no item in KIDSCREEN that focus on other family members, such as siblings and grandparents. Some children also expressed anxieties about the loss, absence, and well-being of family members, but KIDSCREEN does not contain any items on these concerns.

SOCIAL RELATIONSHIPS: FRIENDS AND PEERS

The definition of happiness for many children was spending time with friends. Friends were valued for the practical help and emotional support they provided, but their main function was companionship: people with whom to share time, interests, and activities. Several children yearned to spend more time with friends, particularly outside school, whereas others identified tensions and difficulties in their friendships and peer relationships which generated feelings of isolation, exclusion, embarrassment, and belittlement. More overt difficulties in peer relationships such as name-calling, taunting, and bullying were common, and several children described how their impairments were often a focus of such behaviour.

Areas such as the quantity of contact with friends and the companionship and support that friends provided are well represented in the KIDSCREEN dimension 'Social support and peers', whereas the dimension 'Social acceptance' also mapped well to children's accounts of overtly problematic peer behaviour. However, having opportunities to spend time with friends within and outside school, being included in the activities of friendship groups, and being treated with fairness and respect by friends and peers appeared particularly important, though these concepts are not explicitly represented in KIDSCREEN.

SCHOOL ENVIRONMENT

Like social relationships, school was a dominant theme in children's responses. School brought considerable enjoyment and stimulation to their lives, particularly through the opportunities it provided for social, extra-curricular, and sporting pursuits. Many children also identified lessons in which they performed well. Several children and most parents commented on how important it was for teachers and school to accommodate children's needs, provide sufficient help, and for the school to be accessible. Aspects that detracted from children's enjoyment of school included worries about their performance and inclusion, particularly in physical education, whereas concerns about safety and mobility were very prominent in the accounts of a few, and parents worried a good deal about the appropriateness and amount of work their children were given.

Children's school-related priorities were well represented in the KIDSCREEN section on 'School environment', which includes general items on relationships and satisfaction with teachers, happiness, and ability to pay attention at school, whereas items in the section on 'Moods and emotions' appears likely to tap into children's general concerns about their performance of certain activities and the pressures they

encounter. Specific issues that were prominent in children's accounts, but which are not explicitly covered in KIDSCREEN, include concerns about safety at school and the extent to which children felt that their needs were appropriately accommodated.

HOME ENVIRONMENT

Home was the other key environment in children's accounts, valued as a place of relaxation, rest, and recreation. In contrast to school, it was relatively free of rules and constraints. For example, children often put aside their mobility devices in the home to use methods like crawling that could not be used to move around in other environments. As a place of recreation, possessions such as computers, televisions, books, and toys played a crucial role in children's home lives. A few appeared satisfied for their lives to be centred on their immediate family, home, bedrooms, and possessions, but most also looked to the opportunities that neighbourhoods brought for social interaction and recreation. Therefore, the inaccessibility of neighbourhood companions greatly detracted from the quality of some children's lives, whereas a few mentioned the lack of amenities, dangers, and other unpleasant aspects of their neighbourhoods. The KIDSCREEN dimension 'Parent relations and home life' does not investigate children's priorities for their home environments, as it contains only one item 'Have you been happy at home?' which is too general, whereas the remaining items focus on parent-child relations.

SELF AND BODY

Children frequently referred to positive emotional states such as being 'happy', having a 'good life', and 'fun'; and a few children used strategies such as adjusting their goals or making social comparisons to generate a sense of personal satisfaction or achievement. Accounts of emotional states that detracted from the quality of their lives were highly varied but prominent themes included: loneliness, exclusion, worry, anger and irritation, boredom, embarrassment, and feeling unsafe or frightened.

Several children spoke with a considerable sense of accomplishment about the things their bodies could 'do', including the extra efforts they made because of their impairments, the strategies or special devices they had mastered to achieve everyday tasks, the assistance that they provided to other people, and the thrills of engaging in daring and risky activities. Some children, mostly younger males, said little or nothing about their impairments or the ways in which their lives might be different from their non-disabled peers, and several parents suggested their child was not aware or did not understand that 'he's different'. About one-third of children reported that they experienced some pain or discomfort; localized tiredness or discomfort in limbs and muscles was also mentioned frequently. A few were very worried about forthcoming medical procedures or spoke about how frequent hospital visits or procedures impinged on their lives, though references to ailments, such as eczema or headaches, were infrequent and brief. Accounts of difficulties in performing physical tasks were common; some children compared their bodies unfavourably with their friends, peers, and siblings and spoke about the dependence, privacy needs, restrictions, and the sense of 'being different' that they experienced.

Several of the feelings discussed at length during the interviews, such as happiness, enjoyment, having fun, tiredness,

loneliness, and sadness correspond directly to the words or phrases used in items within the 'Moods and emotions' and 'Psychological well-being' KIDSCREEN dimensions. However, emotional states that were quite prominent in children's accounts, but not explicitly covered in KIDSCREEN, included feelings of boredom, fear and feeling unsafe, embarrassment, anger and frustration, and exclusion. Children's discussions about their bodies and performance of physical activities mapped most closely to the KIDSCREEN dimensions 'Physical well-being', 'Moods and emotions', and 'Self-perception' and were directly represented by three KIDSCREEN items on: (1) feelings that 'you do everything badly', (2) happiness 'with the way you are', and (3) desire 'to change something about your body'. Friends, peers, and siblings provided a yardstick against which children compared their bodies and themselves during the interviews. The relatively low priority given to health in KIDSCREEN is broadly in line with our findings, as children made only a few passing references to ailments. However, many regularly experienced pain or discomfort and a few had specific worries about hospital which are not represented in KIDSCREEN. The KIDSCREEN dimension 'Self-perception' includes three items related to appearance and clothing, but the children mentioned concerns about appearance relatively infrequently. Finally, an item about feeling 'Full of energy?' may be difficult for disabled children to interpret as accounts of tiredness mostly concerned localized lack of energy (e.g. 'my legs feel tired') which is different to the general fatigue that the item implies.

RECREATIONAL ACTIVITIES AND RESOURCES

A striking feature of children's accounts was the wide range of non-sedentary pursuits, clubs, and outings that they enjoyed, though sedentary pastimes were equally important and were especially valued as a focus for friendships. Recreational possessions such as game consoles and computers were highly valued but most children did not see pocket money as a priority, perhaps because parents or relatives usually purchased such items on the children's behalf. When asked to describe their 'perfect day', children's accounts were united in their focus on enjoyment of resting and relaxing, being with friends and family, and simply being able 'to do their own thing'.

Autonomy was particularly important for many of the older males, and this often took the form of a desire to visit friends or to go out unaccompanied. The emphasis on autonomy as being able to 'come and go' as they pleased appeared less prominent in the accounts of younger children and females, several of whom were very concerned about safety (though there were some important exceptions). Recreational activities were rarely identified as areas that detracted from children's enjoyment of life. Only three children identified lack of finances as limiting their ability to engage in activities or obtain desirable objects. They did, however, encounter other constraints on their preferred activities. These mostly concerned the unhelpful attitudes or behaviour of 'gatekeepers' to desirable activities, and more rarely involved problems such as the inaccessibility of buildings. Children were also reluctant to engage in certain activities because they felt that they were unable to perform them adequately, because they disliked always being corrected or 'told what to do', or because they found the activity uninteresting, disagreeable, or unsafe.

Because of the importance children gave to physical activities, the emphasis on these in KIDSCREEN is broadly

convergent with children's accounts. 'Autonomy' and 'Financial resources' are the other KIDSCREEN dimensions most relevant to children's accounts of recreational activities. Three items, assessing whether children could: (1) do 'things' they wanted in their free time; (2) had opportunities 'to be outside'; and (3) were able 'to choose what to do' in their spare time, map very closely to children's discussions. However, KIDSCREEN gives little prominence to children's priorities for safety, relaxation, sedentary pursuits, and recreational possessions. The importance accorded by KIDSCREEN to the availability of time 'for yourself' and 'to meet friends' within the dimension 'Autonomy' does not map well to children's accounts, as they rarely mentioned 'lack of time' as a barrier to these, though they did encounter a wide range of other barriers. Also, items about 'having enough money' to engage in activities with friends and for 'expenses' within the dimension 'Financial resources' are problematic, as few children regarded finances as a limit on their recreational activities.

Discussion

Our study aimed to compare disabled children's accounts of their well-being with the dimensions of KIDSCREEN, an HRQoL instrument. The findings suggest that KIDSCREEN mapped well to children's accounts and there were many instances where children's priorities corresponded directly to the dimensions and concepts within KIDSCREEN. Some commentators have expressed concerns that early HRQoL instruments gave undue precedence to function and health, at the expense of the environmental, social, and interpersonal aspects of life, which evidence²¹ and social theory^{9,10} suggest are of great importance to disabled people. Our findings suggest that the balance between these different aspects of life in KIDSCREEN is broadly in line with disabled children's accounts of their lives. Additionally, several children had little apparent awareness of, or were notably reluctant to speak about, impairment and disability. We speculate that generic HRQoL instruments such as KIDSCREEN might be better accepted by such children than condition-specific instruments, though research is needed to address this question.

The above considerations of balance and acceptability have to be weighed against other important requirements of HRQoL instruments. One of these is to ensure that the priorities of the populations with which the instruments are to be used are adequately captured.³ Our analysis identified several specific aspects of life that appear to be important to disabled children that are not represented in KIDSCREEN. These included: home life; neighbourhood; family members other than parents; inclusion and fairness in relationships, particularly peer relationships; pain and discomfort; accommodation of children's needs in key environments, including needs for safety and relaxation; and access to recreational resources other than finances and free time.

This study was limited by the absence of a comparison group of non-disabled children. Further work comparing the accounts of disabled and non-disabled children is necessary to better gauge the relative importance of these specific aspects in the lives of disabled children. Importantly, however, disability was only one element of the lives of the children we interviewed. Their accounts provide evidence that KIDSCREEN is a suitable instrument for addressing many of their priorities, though it does have some limitations. Policy-makers and others whose decisions are informed by evidence from such

instruments should acknowledge these limitations.

These findings are encouraging for several reasons that go beyond the assessment of a single instrument. First, they suggest that efforts to include children in the development of HRQoL instruments – as was the case with KIDSCREEN – are likely to ensure a reasonable ‘fit’ between instruments and children’s priorities. Second, they suggest that generic HRQoL instruments can go a long way in addressing the priorities of disabled children. Third, the findings indicate that it is possible to represent children’s priorities in a simple and easy-to-administer questionnaire. In doing so, this study affirms the value of using HRQoL instruments for collecting evidence to inform policy and practice in providing services for disabled children.

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References

1. Ravens-Sieberer U, Gosch A, Abel T, Auquier P, Bellach BM, Bruil J, Dur W, Power M, Rajmil L. (2001) Quality of life in children and adolescents: a European public health perspective. *Soc Prevent Med* 46: 294–302.
2. KIDSCREEN Group Europe. (2006) *The KIDSCREEN Questionnaires. Quality Of Life Questionnaires for Children and Adolescents – Handbook*. Lengerich: Papst Science Publisher.
3. Ronen GM, Rosenbaum P, Law M, Streiner DL. (2001) Health-related quality of life in childhood disorders. *Qual Life Res* 10: 71–79.
4. Detmar SB, Bruil J, Ravens-Sieberer U, Gosch A, Bisegger C, the European KIDSCREEN Group. (2006) The use of focus groups in the development of the KIDSCREEN HRQL questionnaire. *Qual Life Res* 15: 1345–1353.
5. Waters E, Maher E, Salmon L, Reddihough D, Boyd R. (2005) Development of a condition-specific measure of quality of life for children with cerebral palsy: empirical thematic data reported by parents and children. *Child Care Health Dev* 31: 127–135.
6. Matza LS, Swensen AR, Flood EM, Secnik K, Leidy NK. (2004) Assessment of health-related quality of life in children: a review of conceptual, methodological and regulatory issues. *Value Health* 7: 79–92.
7. Eiser C, Morse R. (2001) Quality of life measures in chronic diseases of childhood. *Health Technol Assess* 5: 1–157.
8. Davis E, Waters E, Mackinnon A, Reddihough D, Graham HK, Mehmet-Radji O, Boyd R. (2006) Paediatric quality of life instruments: a review of the conceptual framework on outcomes. *Dev Med Child Neurol* 48: 311–318.
9. Zekovic B, Renwick R. (2003) Quality of life for children and adolescents with developmental disabilities: review of conceptual and methodological issues relevant to public policy. *Disabil Society* 18: 19–34.
10. Metts RL. (2001) The fatal flaw in the disability adjusted life year. *Disabil Society* 16: 449–452.
11. Paterson C. (2004) Seeking the patient’s perspective: a qualitative assessment of EuroQoL, COOP-WONCA charts and MYMOP. *Qual Life Res* 13: 871–881.
12. Colver AF. (2006) Study Protocol: SPARCLE – a multi-centre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. *BMC Public Health* 6: 105.
13. Dickinson H, Parkinson K, McManus V, Arnaud C, Beckung E, Fauconnier J, Michelsen SI, Parkes J, Shirripa G, Thyen U, Colver A. (2006) Assessment of data quality in a multi-centre cross-sectional study of participation and quality of life of children with cerebral palsy. *BMC Public Health* 6: 273.
14. Murphy E, Dingwall R, Greatbatch D, Parker S, Watson P. (1998) Qualitative research methods in health technology assessment: a review of the literature. *Health Technol Assess* 2: 1–274.
15. Davis J, Watson N, Cunningham-Burley S. (2002) Learning the lives of disabled children: developing a reflexive approach. In: Christiansen P, James A, editors. *Research with Children: Perspectives and Practices*. London: Falmer Press. p 201–224.
16. Beresford B. (1997) *Personal Accounts: Involving Disabled Children in Research*. London: The Stationery Office.
17. Strauss A, Corbin J. (1998) *The Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd edn. Thousand Oaks, CA: Sage.
18. Seale C. (1999) *The Quality of Qualitative Research*. London: Sage.
19. Spencer L, Ritchie J, Lewis J, Dillon L. (2003) *Quality in Qualitative Evaluation*. London: Cabinet Office.
20. Richards L. (2002) *Using NVivo in Qualitative Research*. Melbourne: QSR International.
21. Hammal D, Jarvis SN, Colver AF. (2004) Participation of children with cerebral palsy is influenced by where they live. *Dev Med Child Neurol* 46: 292–298.
22. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. (1997) Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol* 39: 214–223.
23. Beckung E, Hagberg G. (2002) Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Dev Med Child Neurol* 44: 309–316.