

# Developing a wellbeing outcome measure for use in economic evaluations of children's services: Identifying domains important to children and young people



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## Contents

Acknowledgements

Glossary

Summary .....	i
1 Introduction .....	1
1.1 Why the work is necessary .....	1
1.2 The research: aims and objectives .....	3
1.3 Ethics and governance .....	4
1.4 Outcomes and outcome indicators .....	4
1.5 Content of report.....	7
2 Methods .....	8
2.1 Literature review .....	8
2.2 Focus group aims, access and sampling.....	9
2.3 Focus group design, operation and analysis .....	10
3 Conceptual and methodological starting points for measuring children’s outcomes.....	13
3.1 Definitions and theories of wellbeing and quality of life .....	13
3.2 Outcome measurement in adult social care .....	14
3.3 Outcome measurement in health economics .....	16
3.4 Existing policy-related frameworks .....	16
4 Measuring outcomes for children and young people – the state of play.....	18
4.1 Findings from reviews of existing outcome measurement.....	18
4.2 Existing domain classifications .....	22
4.3 Methodological and empirical issues.....	23
5 Initial set of domains .....	25
6 Findings from the focus groups and proposed set of outcome domains .....	30
6.1 Responses to the open questions .....	30
6.2 Views about the physical care domain .....	31
6.3 Views about feeling safe and secure.....	31
6.4 Views about school.....	32
6.5 Views about help and encouragement .....	32
6.6 Views about communicating.....	33
6.7 Views about feeling understood and being involved.....	33
6.8 Views about recreation and leisure.....	34
6.9 Relationships with family and relationships with friends .....	34
7 Conclusion .....	36
8 Proposed next steps .....	38

9	References.....	40
	Appendix A Questions, types of economic evaluations, and utility measures.....	48
	Appendix B Research in progress .....	54
	Appendix C Leaflet .....	55
	Appendix D Consent Forms .....	57
	Appendix E Group discussion topic guide.....	59
	Appendix F Group discussion self-completion questionnaire .....	61
	Appendix G Domains in existing social wellbeing, quality of life, health related quality of life and health status measures, surveys and indicators.....	62

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The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.

## **Glossary**

ASCOT	Adult Social Care Outcomes Toolkit
AUQUEI	Autoquestionnaire de qualité de vie enfant image /Pictured Child's Quality of Life Self Questionnaire
CAF	Common Assessment Framework
CAMHS	Child and Adolescent Mental Health Service(s)
CASP-19	A self-reported summative measure of quality of life in old age consisting of 19 Likert scale items using a needs satisfaction perspective
CHIP-AE	Child Health and Illness Profile- Adolescent Edition
CHIP-CE	Child Health and Illness Profile (Illustrated with cartoon-type characters and five graduated circle responses)
CHQ	Child Health Questionnaire
CHU9D	Child Health Utility 9D (paediatric generic preference based measure of health related quality of life with 9 dimensions)
CQOL	Child Quality of Life Questionnaire
CRISP	Children's Rights International Study Project
CWRC	Childhood Wellbeing Research Centre
CYPOC	Child and Young Person's Outcome measure
ECM	Every Child Matters
EQ-5D	EQ-5D is a trademark of the EuroQol Group. It is a 5 level standardised instrument for use as a measure of health outcome
EQ-5D-Y	EQ-5D Youth – a child-friendly self-complete version of the EQ-5D-3L for children and adolescents aged 7-12 years
EU	European Union
GCQ	Generic Children's Quality of Life Measure

HBSC	Health Behaviour of School-aged Children survey
HoNOSCA	Health of the Nation Outcome Scales for Children and Adolescents
HRQOL	Health Related Quality of Life
HUI	Health Utilities Index
ICECAP	Investigating Choice Experiments for the Preferences of Older People CAPability index
ICERs	Incremental Cost-effectiveness Ratios
ICS	Integrated Children's System
KINDL-R	Revised Children Quality of Life-Questionnaire (German language measure)
NFER	National Foundation for Educational Research
NICE	National Institute for Health and Clinical Excellence
NIS	National Indicator Set
NPC	New Philanthropy Capital
OECD	Organisation for Economic Co-operation and Development
OFSTED	Office for Standards in Education, Children's Services and Skills
ONS	Office of National Statistics
OPUS	Older People's Utility Scale
PedsQoL	Paediatric Quality of Life Questionnaire
PSA	Public Service Agreements
PSSRU	Personal Social Services Research Unit
PWI-SC	Personal Wellbeing Index-School Children
QALY	Quality Adjusted Life Year
QOL	Quality of life

SCIE	Social Care Institute for Excellence
SCRQOL	Social Care Related Quality of Life
SDQ	Strengths and Difficulties Index
SEAL	Social and Emotional Aspects of Learning
TACQOL	Netherlands Organisation for Applied Scientific Research-Academic Medical Centre child quality of life questionnaire
TAPQOL- TNO-AZL	Preschool children Quality of Life questionnaire
TedQOL	Quality of Life measure for children aged 3-8 years
TNO-AZL	Children's Quality of life
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations Children's Fund (originally United Nations International Children's Emergency Fund)
WHO	World Health Organisation
WHOQOL	World Health Organisation Quality of Life Project

## **Summary**

Measurement of children and young people's wellbeing has developed considerably in recent years. However, there remains a need for an instrument that can be used as a generic measure of outcomes for use in evaluating children's services. The proposed preference based outcome measure would fill this gap. There has been increasing acceptance of the desirability and utility of measuring users' perceptions, experiences and views to support service evaluation and planning in both adult social care and children's services. The research reported here is a first step towards the development of a potential new tool that would be useful for research and particularly in economic evaluations of children's services and interventions. Such a new research tool would help provide research evidence for policymakers, commissioners and other decision-makers about what works and what is cost-effective.

## **Aims and method**

Our aim in this short piece of research is to identify the domains and dimensions of a potential new outcome scale for children and young people in receipt of children's services. The development work adopted both a 'bottom up' and 'top down' approach. A rapid literature appraisal was carried out to see what information is already collected about children's wellbeing, how it is collected and for what purposes. Domains within existing measures were also reviewed to identify a set of potential domains covering areas of children's wellbeing and quality of life that could be influenced by children's services. Three focus groups were carried out in September 2010 with twelve children and young people in receipt of children's services recruited via Third Sector organisations. The sample was small, but met our aim of including both looked after children and children living with their families. The discussions focused on what outcomes are important to children and young people, and their views about and understanding of the domains and definitions we developed from the literature.

Our approach also drew on the Every Child Matters and United Nation's Children's Rights frameworks. Conceptually we were informed by the requirements of cost-effectiveness analysis – we need a measure that would assess change over time that is due to the intervention being tested – and by the long-standing PSSRU Production of Welfare model that defines the linkages between costs, needs, and intermediate and final outcomes. Particularly useful was the work undertaken to create the EQ-5D, including the youth version, and the ASCOT measure for adults who use social care services. Both are preference-based outcome measures for which self-defined and self-reported assessments are paramount in gauging the effectiveness of interventions. The EQ-5D is commonly used for health interventions whereas the ASCOT measure, like our planned measure, seeks to be sensitive to the impact of low level interventions, including those that might reduce or prevent the need for support.

## **The scope and uses of the proposed measure**

The proposed measure would be generic rather than service specific. It would be child-focused, gather self-report information from children and young people, and focus on their subjective views about areas of quality of life that are important to them as well as being relevant to children's services. It would consist of a short question set that could be included alongside other questions (such as specific functioning assessments or questions about service quality), and would be amenable to being combined with cost information to allow cost-effectiveness analysis. The measure would enable outcomes to be identified and monitored at the individual level, within and across evaluations of

different interventions in the way that health related quality of life (HRQOL) can be measured for adults and children, and social care related quality of life (SCRQOL) can be measured in adult social care.

### **Existing measurement**

Existing measures and collections of information about children's wellbeing and outcomes show considerable variation in purpose, scope, development, focus, length and mode of administration. There are few self-report measures with robust psychometric properties and a proven ability to measure change over time.

Child wellbeing and health measures tend to be objective, to collect information from proxies, such as parents or teachers, and to focus on (in)ability or negative behaviours and to include lots of items. The indicators for the Every Child Matters framework drew on existing routinely collected data, collated at national level and commonly focus on external conditions. Existing survey measures of subjective wellbeing typically include too many items to be easily transferred into a short and easy-to-answer question set, and have not been tested as a valid measure of individual outcome, nor focused on areas that children's services might influence. We also identified a number of reasons why assessing children's quality of life should be thought of differently to assessing adults' quality of life, including their social contexts and power relations, and their relationship with children's services. We identified recommendations for measuring children's wellbeing relating to content, what to avoid and what to include to provide a short child-friendly question set. These will all feed into any future development work.

### **Initial domains developed from reviewing the literature**

Our review found considerable agreement about themes. However, the ways in which these were conceptualised, categorised and defined differed between instruments, depending on their focus and purpose. Based on the review we developed nine possible domains and definitions: physical care; feeling safe and secure; school support; help and encouragement; communicating (including getting the information you need); feeling understood and being involved; recreation and leisure; relationships with family; relationships with friends.

### **Main findings from discussions with children and young people**

The focus group discussions confirmed that a self-report measure focusing on the immediate lives of children and young people would link well with their interests and concerns. Spontaneous responses to open questions suggested that eight of our initial set of nine domains were relevant; getting the information you need/information provision was relatively unimportant to those taking part. The discussions suggested that children's understanding of questions based on our domains would be improved by specifying who might be the source of help or support and by concrete and specific statements.

The focus groups highlighted areas of overlap between the domains and suggested ways in which they could be made more discrete, where some aspects would make more sense if moved to other domains and how some domain specification could be improved and refined. Their views about what was important to their quality of life also raised issues around the scope and coverage of the domains. Some 'extra' domains were identified but are not suitable for taking forward in this measure because they are not directly linked to children's services, for example, looking good.

## ***Domains developed from review and focus groups***

### ***Provision for physical needs, including food and drink, warmth and shelter, clean and adequate clothing***

The children and young people participating in the focus groups sometimes interpreted physical care in terms of self-care when this was not intended. Better ways of expressing what we mean by 'physical needs' need to be developed and tested. Specification of who might be providing enough healthy food and drink, warmth and shelter etc. may help interpretation.

### ***Feeling safe and secure***

This domain was understood and considered important. The children and young people identified feeling safe outside school and in the local area as important. This raises questions about the desired scope of the domain; would it be useful to focus on safety in the home and at school, or to expand this to cover the local neighbourhood?

### ***Whether children and young people can go to school and do the best that they can***

Participants said that being able to go to school and do the best you can at school was important. The discussions highlighted overlap between this and the 'help and encouragement' domain. We propose that help and encouragement from teachers be included in the help and encouragement domain and that this domain focus on the outcomes of going to school and achieving potential. While domains may be inter-dependent it is important that they are conceptually clear and understood consistently.

### ***Receipt of help and encouragement to be confident, to make friends, to do well at school and to deal with problems and pressures***

Participants suggested that this domain should specify who might be providing help and encouragement, such as parents, family, friends, foster carers, counsellors, and school teachers and that it cover support to be confident, to make friends, and to do well at school as well as to deal with problems and pressures.

### ***Being able to express yourself, being given the opportunity to have your say (by adults, such as a parent) and being able to challenge decisions***

The domain needs to be made more specific, concrete and distinct. Being able to express yourself is likely to be understood more easily than being able to communicate. Having a say resonated with participants and could cover confidence and issues related to communication difficulties. Getting the information you need to make decisions did not appear to be relevant to this group but could be explored further since it is an important focus of children's services.

### ***Being listened to, able to make choices and have your views taken into account***

The domain needs to be framed carefully so that it is understood as relating to adults. Wording needs to focus on the aspects identified in our initial definition rather than the heading 'feeling understood and being involved', because these terms did not seem to capture what was intended. The domain could focus on being listened to, being able to make choices and have your views taken into account, that is, things that are dependent on others rather than a child's ability to express themselves.

### ***Having enough time to do the things you want to do after school and at the weekend***

The children and young people said unstructured activities are important to them, such as playing and having time to be on your own, and these should be included as examples.

### *Relationships with family and Relationships with friends*

Having relationships with relatives and friends was said to be important. Further work is needed to find a good way of expressing 'enough contact with' and of capturing the notion of high quality relationships.

## **Conclusion**

Research evidence on the effectiveness and cost effectiveness of children's services is vital for outcomes-based commissioning. There is currently no standardised, validated and practical research instrument that measures children and young people's outcomes of interventions, and has the properties required for economic evaluation. The literature review and focus groups helped us identify domains of wellbeing that are relevant to children and young people, to refine the coverage of the domains, and to identify recommendations for the future development of a questionnaire. The review of existing measures and domains helped us get an overview of current measurement of children's wellbeing and outcomes and identify a range of methodological and empirical issues. Existing outcome frameworks and conceptualisation of domains helped us develop an initial set of domains or areas of children's lives likely to be relevant to them and to children's services. The focus groups helped develop some of the ideas within and across the quality of life domains and identify parts needing refinement. The discussions suggest understanding would be improved by identifying who might provide or support each outcome. The work has helped us devise a set of domains that can be developed to measure the effect of children's services on the lives of children and young people.

## **Proposed next steps**

It is suggested that further work should be undertaken as follows to develop the outcome measure.

- Further qualitative work with more children in different circumstances and with experience of different services is needed to confirm and refine the proposed domains into a set of questions and response options.
- A small pilot study and in-depth cognitive interviews to test the questions against their measurement objectives, to find out whether it is practicable for children and young people to complete and to explore whether different versions are needed for different age groups.
- A quantitative study is needed in the longer term to test the psychometric properties of the measure.
- To attribute preference weights to different outcomes a large scale study of adults and the service users is required.

# 1 Introduction

The aim of this research is to identify the domains and dimensions to be developed into an outcome measure that can be used in economic evaluation across a number of children's interventions and services. The work, therefore, crosses three boundaries. First the methods underlying economic evaluation, second research-based outcome measurement particularly that related to wellbeing and quality of life, and finally service provision which in turn is monitored by national and local government. Focusing on existing reviews of outcome measures we identified an initial set of domains. These were discussed in focus groups with children and young people to see if they 'made sense', were important to them and whether they needed any revision or addition.

## 1.1 Why the work is necessary

Resources are always constrained; there is never enough money or staff or buildings to meet all needs in society. Economic evaluation can provide useful information for policy-makers and commissioners as they have to select what services should be provided for a given population. While economic evaluations are becoming more common within health services, and in adult mental health care, they are much rarer in social care services. The recent evaluation on Individual Budgets, for example, was one of the first economic evaluations in adult social care based on a randomised controlled trial (Glendinning et al., 2009). For children's services, cost-effectiveness analyses are even rarer with just a handful of recent studies (see, for example, Muntz et al., 2004; Byford et al., 2007).

The current economic downturn dominates many decision-makers thoughts today and is likely to lead to fewer public sector resources being made available. Leading up to the Spending Review there has, therefore, been a considerable focus on showing how to spend resources wisely, often looking for services that will 'pay off' in the short- or longer-term. Recent work on parenting programmes provides a good example. Some parenting programmes have been shown to be effective in the short-term for children with conduct problems. By linking these improvements in behaviour to changes in the way services are used in adolescence and young adulthood, modelling studies have shown that these are likely to be cost-saving within about seven years (see for example, Bonin et al, 2010).

However, by October 2009, information on more than 150 different parenting programmes/approaches were recorded by the National Academy of Parenting Research <sup>1</sup>. Staff costs range from around £150 to £10,500 per programme (Puig-Piero et al., 2010) but for only a few is there sufficient evidence to say with any certainty that they work and under what conditions. Thus, while parenting programmes as a service genre may be a good investment because of the potential future cost savings there is as yet insufficient evidence to suggest *which* parenting programme(s) will, given a limited budget, be better at improving outcomes for children and young people. So, while commissioners currently have a wide range of programmes to choose from, there is little evidence on which work best for families living in their area and at what price. Moreover, there is a serious deficit of research evidence that could help decision-makers consider whether to purchase any of the parenting programmes or another type of early intervention service.

It is here that economic evaluation has a role – in assessing which services or interventions may be more cost-effective. The reasons for the lack of research information on the costs of children's services

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<sup>1</sup> <http://www.cwdcouncil.org.uk/working-with-parents-and-families/commissioning-toolkit>

have been well-rehearsed (Beecham, 2006, Beecham and Sinclair, 2007), but cost-effectiveness evaluations also require a standardised measure of the *effects* the service may have on those using it. This type of research-based outcome measure needs to capture the change in the 'health and wellbeing' (broadly defined) for the children and young people that is the result of using a particular service or intervention<sup>2</sup>. Many evaluations of children's services to date have used specially designed schedules that address the particular aims of the project, some of which we identify in subsequent parts of this report. Others have used schedules that assess particular facets of 'health and wellbeing' – perhaps using the Strengths and Difficulties Questionnaire to assess change in behaviour problems. Too often, the effects of a service or intervention are not measured in a way that is compatible with an analysis that aims to combine costs and outcomes (such as a cost-effectiveness analysis).

The proposed measure will differ from existing tools and approaches within children's wellbeing measurement. Recent measures have taken the form of questionnaires that focus on children's health and wellbeing or quality of life in general. They do not focus on outcomes that can be supported by children's services. The Children's Society, for example, has developed a self-report instrument that measures and monitors children's wellbeing over time (Rees et al., 2009). It provides a measure of overall life satisfaction and happiness in relation to 10 domains of wellbeing. The data can be used to identify broad trends overtime within large samples. The questions in the survey were not intended to focus on outcome areas that can be influenced by children's services. Nor was the questionnaire designed to assess change in individual children's functioning or capabilities for use in evaluations of interventions. Similarly, the recently discontinued Tellus survey focused on providing information to assess progress towards National Indicators (NI) and Public Service Agreement (PSA) targets (Chamberlain et al., 2010). It included questions about eating healthily, receipt of helpful information about being healthy, substance misuse, experience of bullying, participation in positive activities and satisfaction with parks and play areas. It gathered information across the five Every Child Matters outcomes but was not intended to be used in evaluations of interventions. The Kidscreen questionnaires for children and adolescents and their parents provides another useful comparator. There is a short version that can be completed within 10-15 minutes (KIDSCREEN -27). The questionnaire focuses on health-related quality of life and includes physical wellbeing, financial resources, school environment and bullying (The KIDSCREEN Group, 2004a). Our proposed measure excludes physical health because there are already measures available to evaluate the impact of services in relation to health outcomes. Our approach to domains also differs as we intend to focus on outcomes. So, for example, final outcomes might be influenced by the school environment but school environment is not an outcome of children's services. Similarly, a domain covering feeling safe and secure, might cover being free from bullying, but experience of bullying would not be a domain in itself (The KIDSCREEN Group, 2004b).

A composite measure of how children and young people's outcomes are influenced by services that produces a single continuous score will allow information about outcomes to be linked to costs. Outcome schedules or surveys with lots of separate indicators that do not produce a continuous quantitative score allow costs and outcomes to be described alongside each other, but do not allow the more useful techniques in economic evaluation to be used. Often they do not allow incremental cost-

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<sup>2</sup> The implications of this statement for research design are not discussed here. Suffice to say that it requires a 'control' or comparison group and data collected before the intervention is used and at least once more after a specified time over which the intervention is likely to have an effect.

effectiveness ratios (ICERs) to be presented; these show the cost per additional unit of outcome gained. Neither can techniques like cost-effectiveness acceptability curves be used. These can show the probability – perhaps a 50% or 75% chance – that a particular service is more cost-effective than the comparator. Each of these provides vital information to commissioners and providers as they marshal the range of facts required to make a decision about how best to serve children and families in the context of limited budgets. Appendix A contains more information on economic evaluation and the type of questions that can be answered.

## **1.2 The research: aims and objectives**

The overarching aim of this project was to take the first steps towards developing an outcome measure for use in evaluations that is relevant for children and young people and the outcomes they may derive from various non-health care interventions and supports, and that provides outcome data in a form that is compatible with cost-effectiveness analysis.

Three broad tasks have been undertaken:

- The recent literature on outcome measurement has been reviewed.
- An initial set of domains has been identified.
- Focus groups have been held in which children and young people have discussed and developed these domains.

This research forms the first phase needed to develop a broad-based ‘gold-standard’ tool. The Child and Young Persons Outcome (CYPOC) measure would capture the self-reported impact of the service or intervention in a quantitative form along dimensions that are important to them and that are likely to have an impact on their welfare, quality of life and wellbeing. Taking a preference-based approach, the scores from the CYPOC would be assessed in the context of preferences among young people and adults for each possible state. This allows the multiple domains in the measure to be weighted and combined into a single index, in turn facilitating a full economic analysis that brings together cost and outcome measures.

Thus, the long term objective for this work is to develop a new research instrument that:

- Measures aspects of children and young people’s lives that can be influenced by children’s services.
- Includes domains that are important to children and young people.
- Can be used across client groups, interventions and services, from, for example, residential care for looked after children through to low level early intervention support for children in need, and those with a wider remit – perhaps school based – that are more akin to public health interventions.
- Consists of subjective items that can be collected via self-report (that is, it is practical and easy for children and young people to answer without help and within a short time).
- Meets measurement property standards in terms of reliability, validity (content, face and structural), responsiveness and interpretability.
- Consists of scaled items that are suitable for valuation; is a preference based measure for use in economic evaluations and to support resource allocation decisions.
- Is sensitive to changes in welfare and wellbeing derived from services and support, and thus should be completed before and after services or interventions are used.

It is important that the outcomes assessed by CYPOC should be both focussed on capturing the intended consequences of children's service interventions and be broad enough to capture any unintended consequences.

In the long run, the new measure would aim to support cost effectiveness evaluations of a wide range of children's services delivered by public or independent sector agencies. A detailed classification of children's services can be found in a report by Soper and colleagues (2006). Examples would be:

- Targeted children's services interventions (i.e. those that require a referral) that support children and young people living in their families or independently, such as behavioural programmes.
- Targeted services for looked after children, such as independent visitors.
- Targeted services that meet children's additional support needs, such as services for children with disabilities.

The decision to use a self-report measure means that the interventions or initiatives studied need to produce outcomes that affect children and young people's experiences directly; the measure would be inappropriate for interventions that relate only to improving the quality of existing processes unless the change is likely to have an impact on children's experiences. Similarly, the measure would be unsuitable for assessing the outcomes of policy changes to the roles undertaken by different agencies.

The CYPOC measure need not be the sole outcome measures used in research. It would be suitable for use alongside other questions, such as those assessing health outcomes or service quality, in a similar way to how the EQ-5D is often used in health research.

### **1.3 Ethics and governance**

The project was approved by the Research Committee Ethical Panel within the School of Social Policy, Sociology and Social Research at the University of Kent. The University of Kent agreed to act as the research sponsor. Given that the potential research participants were children and young people with experience of children's services within Kent, the project was also submitted for review by Kent County Council's research governance panel. Written consent was sought from individual children and young people taking part in the focus groups, as well as from their parents or guardians.

The work underlying this report has been undertaken by researchers at the Personal Social Services Research Unit (PSSRU), University of Kent as part of the research programme of the Childhood Wellbeing Research Centre (CWRC), which is funded by the Department for Education (DfE), formerly the Department for Children, Schools and Families.

### **1.4 Outcomes and outcome indicators**

Our starting point is that to measure outcomes in children it is both valuable and possible to collect the subjective views of children and young people via a self-report measure. It is generally accepted that quality of life, and health related quality of life are subjective constructs and consist of personal perceptions, rather than being an observable construct that can be externally evaluated (Ravens-Sieberer et al., 2006). Parker and colleagues argue that

Children's own wishes and desires may be different (to adult interpretations of the outcomes that are of special importance) and reflect the kinds of outcomes that matter to them. Children's

immediate wishes should not be disregarded unless these are seen to conflict with their own long-term interests; not only is a child's present sense of well-being an intermediate outcome of value in itself, but it will also have an influence on future development (Parker et al., 1991, p24).

Statham and Chase note that subjective indicators, based on individuals' self-reports of wellbeing, are increasingly recognised as important for policy development to augment objective measures (Statham and Chase, 2010).

We draw broadly on the *Production of Welfare* approach which provides a theoretical basis for linking resources, needs and outcomes when analysing equity and efficiency in social care (Knapp, 1984, and as applied to child social care see Beecham, 2000). Figure A shows the linkages between resources, such as staff and buildings, which can be combined in many ways to create services (also called intermediate outcomes or outputs). Measures of intermediate outcomes may include items such as caseloads, number of beds or places, or throughput. Costs are a summary measure of the way the resources are combined.

**Figure A**

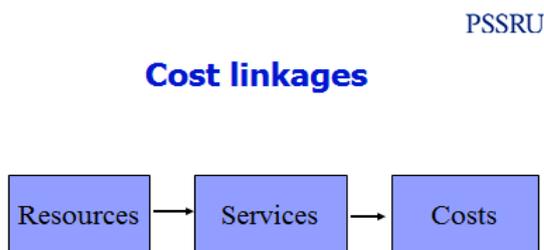
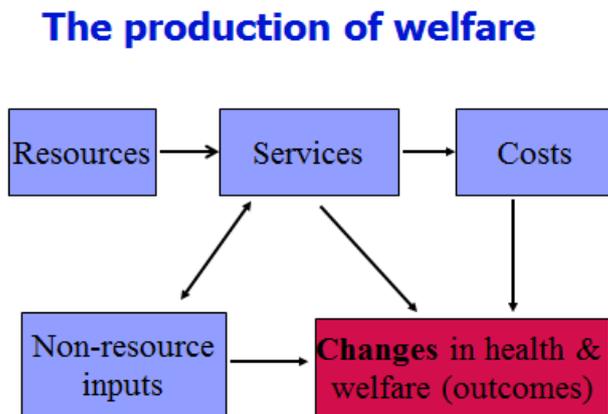


Figure B shows a much simplified model of how these resources generate final outcomes, through links with *non-resource inputs*. Non-resource inputs are factors such as the skills and qualities of the staff, the care environment, or the characteristics and needs of the users which cannot be summarised as a cost measure but which have an impact on *final outcomes*. It is recognition of this link between costs and final outcomes that informs our approach to developing an outcome measure for cost-effectiveness evaluations in children's services.

Figure B

PSSRU



The production of welfare model recognises the difference between ‘final outcomes’ measured in micro- or user level research and ‘outcome indicators’. Improving outcomes for children and young people is high on the policy agenda. Monitoring such policy initiatives commonly relies on *outcome indicators* derived from routinely collected data that summarises activities in local areas or in countries<sup>3</sup>. Commonly these are ‘process’ or ‘intermediate’ outcomes, linking to the performance and quality assessment framework. A range of activity indicators has been identified for each category of children’s social services intervention (Soper et al., 2006).

In the UK, a local index of child wellbeing has been created by collating small area data from, for example, the Census, Hospital Episode Statistics, and the Children in Need survey (Bradshaw et al., 2009). Such ‘external’ measures provide the basis for evaluating progress at a national level or between local authorities. Internationally there is much activity on this front and a number of approaches have fed into our work but are not discussed in detail. The 2007 UNICEF study collated objective wellbeing indicators for a cross-national comparison such as children living in homes below the poverty line, or where there was no adult in employment (Bradshaw et al., 2007, Unicef Innocenti Research Centre, 2007). The OECD Family Database collates 52 indicators under four domains (Adema et al., 2009), the Multi-national Project for Measuring and Monitoring Children’s Well-being (Ben-Arieh and George, 2007) has 60 indicators in five domains, and the Youth Well-being Index (US) includes 28 indicators in seven domains. The International Society for Child Indicators (ISCI) has launched a journal and book series, and held a number of annual conferences. Sessions on child indicators and improving child wellbeing are also increasingly featured at other international conferences.

While child indicators tend to consist of information that is collected about rather than from children and young people, and often focus on external conditions (that is, they collect information at the

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<sup>3</sup> Although a notable exception is the large Tellus survey which used the DCSF ECM outcome framework to structure a self-report questionnaire administered in schools. TellUs was carried out in 2006, TellUs2 in 2007, TellUs3 in 2008 and TellUs4 in 2009 (Chamberlain, et al., 2010).

meso/objective and macro, rather than micro subjective level) that can be aggregated to the national level, they are nonetheless linked to concerns about improving children's subjective experience and sometimes try to take this into account. These domains and dimensions are not detailed here but are part of the broader knowledge base that informs the work. There is much debate about using 'subjective indicators' at this level of aggregation (International Society for Child Indicators, 2009).

In developing our domains, the research behind two existing measures of final outcomes was also important. We build on previous PSSRU experience in developing a preference weighted measure as part of the Adult Social Care Outcomes Toolkit (ASCOT). The properties, domains and types of results supported by this measure are briefly described in Section 3.2 as part of a more detailed outline of conceptual starting points. We also took into account the need for a preference based measure, as advocated for economic evaluation of health care which allow, for example calculation of the cost per quality adjusted life year. Linking to policy for children and young people, our approach to domain specification also sought to take account of both the then DCSF Every Child Matters strategy and the United Nation's Children's Rights frameworks, and again these are summarised in Section 3.

## **1.5 Content of report**

Section 2 discusses the methods used in this study and section 3 describes the findings from the review of the literature. This focuses on existing reviews and discusses survey and research instruments to illustrate the current state of play in outcome measurement in children's services. Although we discuss some healthcare and clinical schedules a full systematic review has not been undertaken due to time constraints. Section 4 discusses in more detail health and social care outcome measurement, highlighting the considerable variation between existing measurement scales, some general findings from our review of existing domain classifications, and some of the methodological and empirical issues. Section 5 lays out our initial domains, identified from the work described in the previous sections and Section 6 describes the response from the focus groups and the subsequent implications for the initial domain set. The two last sections are relatively short and lay out the work required to develop the CYPOC measure and some concluding comments.

## 2 Methods

The project uses two main methods to identify domains for the children and young people's outcome measure, a literature review and focus groups. Focus groups are often used to explore subjective meaning and understanding and are particularly useful to identify relevant domains when developing questionnaires (Morgan, 1997). Focus groups have been used successfully to explore the perspective of children and young people in health, education, and psychology research (Porcellato et al., 2002; Ellermann, 2007). There is also a growing body of work that has used focus groups to understand how children and young people perceive quality of life and health-related quality of life (Beresford, 2009; Beresford et al., 2007; Chavez et al., 2007; Counterpoint Research, 2008; Detmar et al., 2006; Ronen et al., 2001; Stevens, 2008;), including the development of the World Health Organisation Quality of Life (WHOQOL) disabilities module (Power et al., 2010).

### 2.1 Literature review

In the timescale for this first phase of the research, a full systematic review of all literature on outcome schedules for children and young people would not have been possible. Our aim – to identify the domains of a new CYPOC measure – was built on a rapid assessment of five areas of existing literature identified in the research proposal.

- Policy and practice related publications including papers linked to the seminal Every Child Matters Consultation and Green Paper (Department of Health, 2003; House of Commons Education and Skills Committee, 2005), other documents leading to the 2004 Children Act, and including the Framework for the Assessment of Children in Need and their Families (Department of Health et al., 2000) and the subsequent Common Assessment Framework.
- Published evidence about children's views and perspectives on outcomes from previous consultations and academic research (for example, Commission for Social Care Inspection, 2007).
- Recent reviews of outcome measurement such as the reports linked to the Atkinson Review (Soper et al., 2006; Soper et al., 2007) and those that consider the use of utility or health status measures with children and young people (e.g. Petrou, 2003), education measures (e.g. Husbands et al., 2008a, Husbands et al., 2008b), and mental health schedules (e.g. Wolpert et al., 2008).
- Existing reviews of information on children's wellbeing including reports funded by the DCSF (Counterpoint Research, 2008; Statham and Chase, 2010), voluntary organisations such as the recent *Guide to Measuring Children's Well-being* (Thompson and Aked, 2009), as well as international work by OECD (Organisation for Economic Co-operation and Development, 2009a).
- Existing outcome measurement scales, schedules and surveys focusing on children's wellbeing, quality of life, health-related quality of life and health status.

References cited in the key policy documents, reports and journal articles were in turn reviewed, and websites searched to identify further publications, or outcome measures that might include domains of interest. We also searched research registers to identify work in progress such as the Social Care Institute for Excellence's (SCIE) Research Register for Social Care and the National Foundation for

Educational Research (NFER) Current Education and Children's Services Research (CERUKplus) database. Appropriate websites were also searched, including international and national organisations and academic research units and those reporting recent conference proceedings (see Appendix B, which highlights the projects found by type of research/study).

## **2.2 Focus group aims, access and sampling**

We set out to recruit sufficient participants for two or three focus groups with an *ad hoc* volunteer sample drawn, where possible, from current service users aged between 11 and 16. We wanted to involve both looked after children and those supported in their families or living independently. Young people with communication difficulties, learning difficulties, or additional support needs and those who could not provide informed consent were excluded due to time and resource constraints, but would be included in later stages of the CYPOC development.

Children in receipt of services can be hard to reach; they are a relatively small and dispersed population and researchers usually have to approach them indirectly following complex access negotiation (Wigfall and Cameron, 2006). We found that contacting and involving our eligible sample posed a number of practical challenges, which had an impact on the timing and progress of the fieldwork. From the outset we anticipated that we would ask existing groups, and fora to make initial contact with children and young people on our behalf and to invite them to participate. A similar approach had worked well in our earlier research with young carers (Holder et al., 2009).

Gaining approval and the necessary support from the local authority and provider organisations was time-consuming, took longer than anticipated and relied on considerable goodwill. Re-organisation of the children's services following the change in government meant that it was a difficult time: senior management were involved in organisational change and staff within provider organisations were covering vacant posts and adapting to changing roles.

Kent Children's Services gave permission for the research to take place within their service array in June 2010, with the proviso from the Heads of Service that social workers were unable to give any time to the project. It was suggested that the research be introduced to the county's Children in Care Council. Our understanding was that members of this group might take part in the research, however it transpired that they would review the project with a view to endorsing it and that this would be useful when approaching potential participants.

The Children in Care Council approved the project as worthwhile, in mid-July, over three months after the project started. The local authority then identified two voluntary sector organisations as potentially willing and able to help recruit 'looked after' children and young people. The first ran an advocacy and support group for looked after children and the second provided mentoring for care leavers aged sixteen and over but at the time of the research did not offer regular meetings or activities. It took between six and ten weeks from our first contact at senior management level to obtain the names of frontline staff in contact with children and young people.

We also identified a voluntary sector organisation that provided independent living support, family support and support to enhance community engagement among children and young people in the South East. We were helped by staff running a community project providing one to one support, group workshops, school clinics, parent support groups and family mediation, and a range of activities for young people and their families.

We provided the organisations with user-friendly leaflets (see Appendix C) and consent forms (see Appendix D) to forward to young people and their parents or guardians. These were adapted from earlier work in Kent with young carers (Holder et al., 2009). Staff were aware that we would offer a £10 gift voucher as a 'thank you' but this was not mentioned on the leaflet.

It was difficult to obtain information about the size and characteristics of potential samples, and the number of children and young people who were excluded. At two of the organisations, contacts who had identified eligible participants asked social workers or key workers whether there were any reasons for not approaching them. Reasons given by the third sector organisations for excluding children from the outset included extreme shyness. Screening by key workers was said to be important to ensure that young people were not contacted at an inappropriate time, such as when involved in child protection proceedings, in jail or in a 'chaotic place', and to make sure that social workers knew what 'their' young people were doing. One organisation reported sending invitations to nine young people from a caseload of 23. Another identified 15 potential young people living in one geographical area, which would help ensure they could attend a group at a convenient location. The third organisation sent the project information to about 70 young people on their mailing list. However, this list included young people who rarely attended groups and few replied. Three young people returned consent forms who attended one particular group and the regular attendees at this group were then contacted again with a view to arranging an interview at their group.

We faced further delays in making contact with potential participants when opportunities to talk about the research were postponed and because of uncertain attendance at planned events and meetings. Moreover, the delays to our timetable meant that the fieldwork would occur either during the summer holidays or at the start of the new school term. Both proved to be busy periods for young people in contact with the participating organisations.

Quite quickly it looked as if the younger ages might be under-represented in our sample; the Children in Care Council consists mainly of young people above our specified age range, and as mentioned above, one of the organisations supported care leavers aged sixteen and over. Given the difficulties associated with involving looked after children we decided to continue to work with the service supporting care leavers.

Arranging meetings also presented logistical challenges. Dates for the focus groups were kept flexible to ensure the best attendance. The dispersed nature of the population also meant that decisions about the venue were made only when staff knew who had volunteered to ensure a convenient venue with good public transport links could be selected.

### **2.3 Focus group design, operation and analysis**

Three focus groups were conducted in September 2010 with 12 young people recruited through three organisations. They included eight boys and four girls. There was always uncertainty around whether those who expressed an interest in taking part would attend on the day, even if they confirmed the night before. This made estimating the number who dropped out difficult. As far as we can tell at least six recruits opted out at the last minute. Although a small number of participants, and despite the challenges in obtaining the sample, we met our initial aim of discussing domains with children and young people in this preliminary work. Further qualitative interviews could be held as the domains and dimensions are developed.

Two groups included boys and girls and one group was single-sex. The two mixed gender groups included young people who knew each other and who usually met as a group. The single-sex group included boys who did not know each other. Eight of the young people were White British and four were Asian and English was not their main language. All but one of the participants was attending school or college.

The groups included three, four and five young people. Vaughn and colleagues (1996) recommend group interviews with children be smaller than for adults, usually five or six participants. Fortuitously, given the volunteer nature of the participants, the groups were roughly stratified by age, insofar as none included both the youngest and oldest ages specified. However, as anticipated the younger ages were under-represented; there were only two eleven year old participants. The rest of the sample were aged between thirteen and sixteen, apart from one care leaver who was 17.

The key worker for the participants who were living with their families provided a general description of the reasons for their referral to the service and these included anger management, behaviour issues at home or school, family breakdown, low self-esteem, low confidence, and or no friendship circle. In school, two members of the group were on reduced timetable as a result of poor behaviour, all had encountered bullying and had difficulties making or keeping friends and two had dyslexia.

The focus groups took place during the first few weeks of the new school term-time after school. Two were held during existing meetings, at venues where the young people usually met. The meeting specially arranged for the focus group with care leavers was held at a family centre.

The same moderators attended each group discussion. Each session was audio-recorded and lasted between thirty-five and forty-five minutes. At each group, soft drinks were available throughout. In one group, the young people took a break to have a rest and a snack. At another group, pizzas were provided afterwards.

At the start of the group, the project and the aims of the discussion were outlined. Confidentiality and anonymity were explained. Permission for audio-recording was requested, and the ground-rules of group discussions outlined (including the voluntary nature of participation, that it was not a test with right or wrong answers, and different views were encouraged etc.). Consent forms were collected. The groups started with an 'ice-breaker' activity, which was designed to help participants relax and to be of general relevance to the topic. Participants, including the moderator/researchers took it in turns to introduce themselves, and tell the group the best thing they had done over the summer and what they were looking forward to over the next month or so. A structured topic guide was used by the moderator (see Appendix E). It included open questions similar to those used in a study of disabled children's understanding of health related quality of life (Beresford, 2009; Young et al., 2007). A shorter version of the moderator's topic guide was circulated to the group. Open questions were asked first, and then possible domains of life were circulated and/or pinned to a flip-chart to review; an approach also used to explore the relevance of HRQoL domains to Asian children (Wee et al., 2006). These were the initial nine domains identified in section five. The meaning, relevance and coverage of each was discussed using pre-set and impromptu probes and participants were asked if anything important was missing from the list. To encourage and maximise participation participants were asked to provide more detail, to elaborate further or to comment on something another participant had said.

At the end of the interview, participants were asked to complete a short form asking for basic characteristics such as age, gender and ethnic group (see Appendix F). They were given a £10 voucher for High Street shops to thank them for their time and contribution to the project.

While most of the participating children and young people were co-operative and helpful and tried hard to remain on topic, the review of all nine domains within each group proved quite burdensome. Any future work might address this by exploring a subset of domains with different groups. There was no noticeable gender effect on the communication within the mixed gender groups.

Data from the focus groups was transcribed and analysed thematically using a qualitative software package (NVivo8).

### **3 Conceptual and methodological starting points for measuring children's outcomes**

In this section we provide a brief overview of the conceptual definitions and theories of wellbeing and quality of life before describing recent developments in the measurement of adult social care outcomes. We also introduce an outcome measure used in economic evaluations of health care. Lastly, we note important facets of two key frameworks for thinking about children's outcomes: the then DCSF Every Child Matters framework and the United Nation's (UN) Children's Rights framework. Each of these informed our thinking.

#### **3.1 Definitions and theories of wellbeing and quality of life**

Historically, conceptions of wellbeing developed out of a movement to de-medicalise health. Statham and Chase (2010) suggest wellbeing is dynamic and does not equate to being happy; 'wellbeing', 'life satisfaction' and 'quality of life' are often used interchangeably. Currently, there is no single agreed definition of wellbeing and although linked, each definition cited below highlights a slightly different approach.

A state of wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (World Health Organization, 2004).

Being able to develop psychologically, emotionally, intellectually and spiritually; initiate, develop and sustain mutually satisfying personal relationships; use and enjoy solitude; become aware of others and empathise with them; play and learn; develop a sense of right and wrong; resolve (face) problems and setbacks and learn from them (Mental Health Foundation, 1999).

A positive physical, social and mental state; it is not just the absence of pain, discomfort and incapacity. It requires that basic needs are met, that individuals have a sense of purpose, that they feel able to achieve important personal goals and participate in society. It is enhanced by conditions that include supportive personal relationships, strong and inclusive communities, good health, financial and personal security, rewarding employment, and a healthy attractive environment (Defra, 2010).

Similarly, childhood wellbeing is defined in many ways. A report on the use and function of the term 'wellbeing' within discourses across Whitehall (Ereaut and Whiting, 2008 p5) highlights some of the numerous questions and issues embedded in different constructions of the concept, including whether it is:

- Individual or collective?
- Subjective or objective?
- Permanent or temporary?
- General or specific?
- Reducible to components, or an irreducible holistic totality?
- Whose responsibility? (structure vs. agency)
- A neutral state (nothing wrong) or a positive state (better than neutral)
- A state or a process - a place or a journey?

- An end in itself - or necessary to another end?

The authors conclude that the default or 'operationalised' use of the term wellbeing within the DCSF was in relation to the five DCSF Every Child Matters (ECM) outcomes. However, within different policies and discussions, different versions were found to be evident. These include:

- a 'philosophical' version, characterised as an idealised aspiration concerned with fulfilling potential, and evident in discussions of what constitutes a 'A Good Childhood';
- a medical version, which acknowledges that health is more than bodily health, found within CAMHS, SEAL and the DCSF ECM outcomes concerned with being happy and healthy;
- a sustainability discourse within Defra;
- a relatively recent discourse of holism, with a focus on the whole child, family and school system.

If we look at the linked Quality of Life (QOL) concept a similar range of definitions and inclusions can be found: position in life; functioning; feelings about functioning; existence; discrepancy between actual and ideal self (Davis et al., 2006). The authors argue that health status, functioning and caregiver difficulties are theoretically different from QOL, however health status and health related quality of life were included in this review.

Davis and colleagues (2006) argue that in relation to children and young people, QOL should refer to how a child feels and not what they can do or their ability to perform tasks and activities (functional status), which may be unrelated to how they feel. They highlight three main theories underpinning the various definitions and the strengths and limitations of each:

- discrepancy theory fails to provide insight into why children might feel unhappy;
- utility theory, which is used in the Health Utilities Index measurement of health states<sup>4</sup> is useful in cost-effectiveness studies;
- Lindstrom's model of quality of life, which has the advantage of covering global, external, interpersonal and personal influences, also has the disadvantages of lacking subjective items and omits important domains, such as social and emotional wellbeing.

Some authors suggest that QOL in relation to children is 'not only concerned with how children fare, but also with contributory factors such as material goods, relationships, a pleasant living environment, and so forth' (Skevington & Gillison, 2006 cited in Axford, 2009 p374). Conceptual distinctions highlighted between adult and children's health related quality of life are also noted: children are 'embedded within multiple social contexts including the family, the child's peer group, the classroom and the community'; in particular the context is different for children for they have less power than adults to influence their context or change their environment (Matza et al., 2004 p80).

### **3.2 Outcome measurement in adult social care**

Outcome measurement in the adult social care sector provides some pointers for the way forward for the CYPOC measure, in particular a preference-weighted measure developed at PSSRU as part of the Adult Social Care Outcomes Toolkit (ASCOT: Burge et al., 2006; Forder et al., 2008; Forder et al., 2007; Malley and Netten, 2009). The ASCOT measure is designed to capture information about an

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<sup>4</sup> Among others, including the EQ-5D.

individual's social care related quality of life (SCRQOL), that is, the quality of life outcomes that can be affected by social care activities. It is intended to be applicable across as wide a range of user groups and care settings as possible and to be of use in a variety of research circumstances including social care evaluations, cost-utility analyses, weighted output of government funded social care for National Accounts and policy analysis.<sup>5</sup>

ASCOT draws on eight or nine SCRQOL domains (depending on the service): control over daily life, personal cleanliness and comfort, food and nutrition, safety, social participation and involvement, occupation, accommodation, cleanliness and dignity. There are currently four versions of the measure including an interview format, two self-complete versions and one that draws mainly on observation for use in care homes. The interview version includes questions that are designed to measure current SCRQOL (which quantifies wellbeing in terms of the degree to which they experience a range of needs), whether services help service users in each domain, and a hypothetical question that asks them to rate what their life would be like without the intervention or service, or their 'expected needs'.

The toolkit is designed to support the measurement of outcomes in three ways. First current SCRQOL may be compared in a pre- and post-intervention study design. Second, 'SCRQOL gain' can be estimated by comparing the difference between current and perceived or derived expected SCRQOL in the absence of the intervention. Thirdly, outcomes of prevention and enablement interventions, expected to reduce or prevent the need for support, can be measured by looking at changes in expected SCRQOL in the absence of services ('expected needs') before and after interventions.

Two other outcome measures are useful to mention here, although neither is linked to preference weights. The development of the ICECAP measure for older people included qualitative work with service users to identify factors that could influence their quality of life, such as activities undertaken, relationships, health, and wealth. Five conceptual attributes (attachment, role, enjoyment, security and control) were developed from the user-identified factors, and questions developed with four answer options using terminology such as 'I have all the love and friendship that I want'. This was developed in line with Sen's capability argument (1982) rather than assessing functioning *per se* (Grewal et al., 2006; Coast et al., 2008). The CASP-19 is another measure of wellbeing for adults, again self-reported, and has four domains (control, autonomy, self-realisation and pleasure) with 19 Likert scale items (Wiggins et al., 2008).

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<sup>5</sup> The ASCOT toolkit was developed as part of the ONS-led Quality Measurement Framework (QMF) programme, funded for three years by HM Treasury. This programme of work included three projects on the outputs of particular service areas and the fourth explored the relative importance of the domains of wellbeing via a preference study with service users. The development work built on numerous studies of cost and outcome measurement undertaken over many years and the National Service User Experience Surveys. The ASCOT instrument drew on a literature review, focus groups and cognitive interviews with service users, and consultation with policymakers, local councils, and regulators. This qualitative work supported the development of the domains, and refinement of the domain definitions, question wording and answer options. General population preference weights for the Toolkit were explored using a feasibility study of preference elicitation techniques conducted with service users in cognitive interviews and a survey of 300 members of the general population (Netten et al., 2009) and a large scale preference study with 500 members of the general population using best-worst scaling experiments (Burge et al., 2010). Work continues including further conceptual refinement of the domains and psychometric testing. A time-trade off study is also planned to develop a way of using preference weights to estimate quality adjusted life year (QALY) equivalent weights for social care outcomes.

### **3.3 Outcome measurement in health economics**

Probably the best known outcome measure developed for economic evaluation is the EQ-5D ([www.euroqol.org](http://www.euroqol.org)). The EQ-5D measures health status through a visual analogue scale and a set of five questions scored on a three-point scale. It can be completed in five minutes or so and leads to the identification of (change in) health states due to an intervention. Its value to this project lies in the way it can be computed as a single number - the quality of life enjoyed for each extra year of life gained from an intervention, or Quality Adjusted Life Year (QALY). The QALY is based on the idea of utility – or relative desirability – of different outcomes, or health states. Utility values are derived from population surveys where the respondents are asked to state their preferences for the different health states possible across the five domains using techniques such as Standard Gamble or Time Trade-off (see Drummond et al., 2005). In turn, this ‘utility value’ is then calculated for each person in the study depending on their responses to the EQ-5D. Combining these values with information on the cost (resources used) of achieving those health gains allows calculation of the cost- per-QALY gained for any given intervention. The cost-per-QALY is the metric of choice for National Institute for Health and Clinical Excellence (NICE) and is commonly used in cost-effectiveness evaluations of acute health care for adults. It has been used to evaluate mental health care with some, but not complete success (Knapp and Mangalore, 2007) and its appropriateness for children and young people is much debated (Petrou, 2003) although a youth version is now available (Ravens-Sieberer et al., 2010; Wille et al., 2010).

Perhaps more importantly for this study, the focus of the EQ-5D is health; the five domains measured are mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Many interventions for children – those in education, social care, safeguarding or for children at risk for example – are not intended to influence their health but to have a broader impact on their circumstances and wellbeing.

### **3.4 Existing policy-related frameworks**

Axford (2009) suggests the concept of child wellbeing can be viewed through five different perspectives or conceptual ‘lenses’: need, rights, poverty, quality of life and social exclusion each of which offers what Sen calls ‘analytic advantage’ by illuminating different aspects of children’s lives. Here the rights and quality of life perspectives are the most relevant: the rights perspective focuses on the resources, freedoms and opportunities people and institutions should ensure children have and which may be violated; the QOL perspective focuses on enrichment. Below we highlight particularly useful aspects of the then DCSF Every Child Matters framework and the UN Children’s Rights approach. To a lesser extent our measure also relates to Axford’s social exclusion perspective, in so far as we are concerned with children’s contact and relationships with their family and peers.

#### ***Every Child Matters framework***

The then DCSF Every Child Matters (ECM) Change for Children programme set out a holistic approach to improving wellbeing in children, placing it at the centre of service delivery. The five outcomes were devised as mutually reinforcing universal ambitions for every child and young person and linked to national public service agreements and DCSF Departmental Strategic Objectives: being healthy, staying safe, enjoying and achieving, making a positive contribution, achieving economic wellbeing (HM Treasury, 2003, HM Government, 2004). Improving the outcomes of looked after children and children with special educational needs and disabilities was a key part of the aim to narrow the gap between

disadvantaged children and their peers as set out in the Children's Plan (Department for Children, Schools and Families, 2007). As noted earlier in our review of definitions and theories of wellbeing, the DCSF ECM framework has often been used to operationalise wellbeing (Ereaut and Whiting, 2008).

### ***Children's Rights framework***

The UN Children's Rights framework provides another useful starting point for thinking about outcomes for children and the domains that might be included. The UN Convention on the Rights of the Child (United Nations General Assembly, 1989) grants all children and young people a wide-ranging set of rights, including the right to express their views and have them taken into account in all matters affecting them (article 12); the right to play, rest and leisure (article 31) and the right to protection from all forms of violence (article 19). Some groups of children and young people – for example those living away from home, and young disabled people – have additional rights.

Lansdown (1994, in Taylor et al., 2001) divides the articles contained in UNCRC into three main categories of rights.

- (a) Provision rights—the rights of children to minimum standards of health, education, social security, physical care, family life, play, recreation, culture and leisure.
- (b) Protection rights—rights to be safe from discrimination, physical and sexual abuse, exploitation, substance abuse, injustice and conflict.
- (c) Participation rights—civil and political rights such as a child's right to a name and identity, to be consulted and to be taken into account, to physical integrity, to access to information, to freedom of speech and opinion, and to challenge decisions made on their behalf.

## **4 Measuring outcomes for children and young people – the state of play**

Children's outcomes are explored in overlapping fields of enquiry, including health, health economics, mental health, social care, and education. Information is collected at international, national, and local government level as well as within individual academic research projects or by provider organisations. Information about children's outcomes and wellbeing is collected in a variety of ways, drawing on different sources and serving different purposes. This section highlights some of the main approaches to measuring children's outcomes, and provides an overview of the state of play within broad types of outcome measurement.

### **4.1 Findings from reviews of existing outcome measurement**

There have recently been a number of reviews of approaches towards measuring children's outcomes: as possible indicators of the output of children's services (Soper et al., 2006); children's wellbeing at the societal level (Thomas, 2009); in education (Husbands et al., 2008a); in mental health (Wolpert et al., 2008); in terms of children's happiness, life satisfaction and wellbeing (Thompson and Aked, 2009). Here we draw out findings related to the instruments used to assess outcomes. Challenges in measuring children's wellbeing are summarised in Section 4.3.

Reviews of instruments were identified that compared paediatric quality of life instruments (Davis et al., 2006), health related quality of life instruments (Cieza and Stucki, 2005), instruments for measuring the quality of life of children with chronic illness (Eiser and Morse, 2010), and the suitability of instruments for measuring quality of life in patients with specific diseases, such as cystic fibrosis (Goldbeck and Schmitz, 2001) or acute lymphoblastic leukaemia (Savage et al., 2009). Sections of papers that summarised existing measures as part of developing a new measure were also appraised (Chen et al., 2004; Power et al., 2010) along with articles assessing or explaining the operation of key measures, such as the self-report version of the Strengths and Difficulties Questionnaire (Goodman et al., 1998), the development of a child-friendly version of the EQ-5D (Wille et al., 2010) and the Health Utilities Index (Horsman et al., 2003).

Only a few of the reviews looked at the quality of measures (Pal, 1996; Davis et al., 2006; Wolpert et al., 2008). One review usefully described the types of indicators found, providing background information on how they are used but did not seek to reach conclusions about their methodological rigour (Husbands et al., 2008a). Others more clearly appraise the quality of the measures; of the 113 mental health outcome measures identified by Wolpert and colleagues (2008) just six were considered to be robust but none met the full criteria for measuring severity and change over time. The COSMIN checklist has recently been developed to help in appraising the methodological quality of research instruments (Mokkink et al., 2010).

A total of 61 measures or indicator sets were identified focusing on quality of life, HRQOL, health status and wellbeing of children and adolescents, and a further 16 measures for adults. Box 1 summarises the ways in which instruments can differ (Schalock, 2004; Husbands et al., 2008a; Stevens, 2009). Individual commentators have also noted that: measures of quality of life tend to be age-specific (Chen et al., 2004); that there is a need for positive indicators to counter the deficit indicators (Lipmann, 2007 in Thomas, 2009); and that health assessments often rely on proxy measures (Kurtz, 2003; Macran et al., 2003). Parker and colleagues (1991) discuss the wide range of child care data available, which includes some 'that are associated with public expectations, some that are a reflection of the corporate

nature of social service organisations, others that reflect professional attitudes and beliefs, and yet more that may vary between family members, or from one child to another' (p24).

### **Box 1 Ways quality of life measurement tools and indicators can vary**

- Uses and applications: research, programme evaluation, decision-making (including resource allocation), monitoring standards (for example, national children's services), performance against international surveys, national or regional management or accountability purposes
- Generic or disease and condition specific
- Development top-down or bottom-up
- Child or family focused
- Who provides the information: parent or child report
- Population differences in terms of age groups
- Focus – health status, health related quality of life (HRQoL), subjective quality of life
- Functional assessment or personal appraisal of feeling or capability/capacity
- Focus - external conditions and indicators or self-perceived quality of life or HRQoL; whether focus is on objective or subjective indicators
- Definitions of quality of life
- Number of domains
- Number of items and length
- Choice of scale
- Mode of administration: whether interviewer based or self-completion
- Duration of recall period
- Whether preference based

Recommendations relevant to our work found in the reviews include: that measures should focus on the immediate lives of children and young people and consider their future lives (Statham and Chase, 2010); that a set of around seven dimensions is ideal for a descriptive system, and that it should be no more than nine (Stevens, 2010a); younger children are likely to have difficulties with time concepts, although children over eight are thought to be able to consider reporting a period of four weeks (Ravens-Sieberer et al., 2006).

### ***Routine data collection in children's services***

The Looked After Children (LAC) Schedules collect information related to seven dimensions of children's wellbeing. However, as Bailey and colleagues (2002) note, there are a number of problems when using existing monitoring system data for evaluation purposes: much of the information is concerned with process, some is unconnected to specific outcome dimensions, and some of the LAC schedules, such as the Assessment and Action record implemented in 1995, have poor completion rates (Bailey et al., 2002). The Integrated Children's System (ICS), which built on the Common Assessment Framework (CAF), requires that a minimum data set is collected. While the conceptual

framework and focus on safeguarding and promoting welfare is clearly broader than children's subjective wellbeing and reflects professional concerns relating to child development, the framework covers domains of interest for the current work.

The existing questionnaires and scales that accompany the Framework for Assessment of Children in Need and their Families are aimed at practitioners (Department of Health, 2000). They include several research-based schedules such as the Strengths and Difficulties Questionnaires and the Adolescent Wellbeing Scale, but are of limited use for economic evaluation.

### ***Research instruments to measure health related quality of life and quality of life***

Two preference based measures suitable for economic evaluation are briefly noted here. The adult EQ-5D is probably the most commonly used preference weighted health index and has been described earlier. It is short, just two pages, and can be self-administered. The EQ-5D uses a visual analogue scale similar to Cantril's ladder (Cantril, 1963) to record the respondent's overall self-rated health. The endpoints are 'Best imaginable health state' and 'Worst imaginable health state' (Cheung et al., 2009). An amended version of the Cantril ladder is used in the World Health Organizations's cross-national Health Behaviour in School-aged Children survey (HBSC) to measure life satisfaction (Currie et al., 2004). Young people are asked to indicate the step of the ladder at which they would place their lives at present between the top (scoring 10, the best possible life for you) and the bottom (scoring 0, the worst possible life for you). A score of 6 or more was defined as a 'positive level of life satisfaction.' (Currie et al., 2004 p56). The New Philanthropy Capital wellbeing measure for children also uses a similar approach (Nevill, 2009). Visual analogue scales have been shown to measure change adequately in economic evaluations of children's services (Beecham and Sinclair, 2007). Such a scale would be a good addition to the CYPOC and will be explored in further work.

The Health Utilities Index is another health-status classification system that produces scores of overall HRQOL for individuals, is sensitive to change over time and can also be used to calculate QALYs for cost-utility analysis and cost-effectiveness studies (Horseman et al., 2003). The HUI Mark 2 covers seven attributes: sensation, mobility, emotion, cognition, self-care, pain, fertility. The HUI3 covers eight attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition, pain. There are self-assessment and proxy versions and recall or health status assessment periods can be varied.

A version of the EQ-5D has recently been developed that is more appropriate for children and young people (Wille et al., 2010). Only minor adaptations to the EQ-5D were found to be needed. For example, in the EQ-5D-Y the self-care domain was changed to refer to an age appropriate degree of independence in daily personal care. Similarly, the definition of 'usual activities' was adapted and more appropriate examples provided, including going to school, hobbies, sports, playing and doing things with family or friends. The response options were modified to improve uniformity which resulted in changes to the implied severity of the statements in the original version and the visual analogue scale was given more detailed graduation. This study concluded that the domains were transferable to children but changes were needed to make sure that it reflected health related impairment and not age-related (in)ability. The adaptation made to the adult EQ-5D suggests that Thomas (2009) is correct in her assertion that many indicators for domains of adult and child wellbeing overlap, and that it is the interpretation and weighting of the indicators that it is important to get right.

A study at the University of Sheffield used qualitative interviews with children, aged 7 to 11 years with a range of acute and chronic health conditions, to ask how their health affects their lives and to develop a descriptive system for a new preference-based measure of health related quality of life for children - the Child Health Utility Index 9D (Stevens, 2008; Stevens, 2009; Stevens, 2010a; Stevens, 2010b). This measure is intended to be preference based, but is still in the development stage.

Focus groups are often used to understand children's views. Children's views about health-related quality of life were explored to develop a disorder (epilepsy) specific measure (Ronen et al., 2001), and in a study exploring the extent to which Western measures of health-related quality of life are applicable to Asian children and young people (Grewal et al., 2006; Wee et al., 2006). Focus groups were also used to ask children about what constitutes their wellbeing more generally, in an Australian study interested in developing child-centred indicators (Fattore et al., 2009), and more specifically with disabled children and young people in relation to outcomes from support services (Beresford et al., 2007).

Children's views are increasingly being sought and reported to feed into policy and practice development. The Children's Rights Director for England, Ofsted and the Rights4me website have conducted various consultations with children and young people and a number of their reports and summaries were reviewed. Counterpoint's qualitative research sought to identify factors comprising a 'Good/Content' childhood (Counterpoint Research, 2008). They found that children and young people identified a similar range of issues as parents and carers (who identified factors in common with the DCSF ECM framework), but used different language. The children and young people identified playing/having fun, getting prizes, stars and praise, feeling protected, cared for and/or loved, being understood/listened to/able to talk to parents, getting the things you want, sports/activities (Counterpoint Research, 2008 p32).

There are a number of available standardized measures of subjective wellbeing. However, they are all limited in terms of our criteria for the new planned measure. The recent Children's Society report (Rees et al., 2009) notes various national surveys that have included self-reported wellbeing, such as the Tellus survey (Chamberlain et al., 2010), the British Household Panel Survey youth questionnaire (Institute for Social and Economic Research, 2009), and a survey of children in Nottingham (New Economics Foundation, 2004). The Tellus survey of children and young people in school years 6, 8, and 10, was developed by Ofsted and, with support from the DCSF, administered by Ofsted as a national survey in 2007 and 2008, and then by the National Foundation for Educational Research (NFER) in 2009 (Chamberlain et al., 2010). It was a self-report survey based around the DCSF ECM dimensions that could be completed online, and included a spoken version.

The Children's Society research programme includes a survey of just under 7,000 young people aged 10-15 in England to assess subjective wellbeing (Rees et al., 2009). Separate versions of the questionnaire were developed for primary and secondary school aged children, and they included 100 and 140 items respectively.

The longitudinal panel survey Families and Children Study (Department for Work and Pensions, 2005) was carried out across England, Scotland and Wales between 1990 and 2008. It included face-to-face interviews with mother and partner (rather than the child) and 69 questions related to children's wellbeing. A report of the 2005 survey focusing on children's wellbeing draws on Sen's capability

approach and identifies items such as the proportion of children who do not enjoy good health, and the proportion with behavioural problems at school (Pedace, 2008).

## **4.2 Existing domain classifications**

Quality of life domains can be defined as ‘the range over which the concept of QOL extends’ (Schallock, 2004 p 205). Schallock found considerable agreement over 16 published studies. Of the 125 domains identified over 70 per cent related to interpersonal relations, social inclusion, personal development, physical wellbeing, self-determination, material wellbeing, emotional wellbeing and rights. Physical and material wellbeing would be excluded from our measure because these are likely to be beyond the influence of children’s services. However, nutrition, along with leisure (recreation and hobbies) and activities of daily living (self-care skills, and mobility) are often present in adult social care outcome measures (such as ASCOT) and are likely to be relevant to children and young people in receipt of services.

The recent Children’s Society survey drew on responses to open questions asking young people what ‘makes for a good life’ and what stops young people having a good life. Ten key responses were identified (family, friends, leisure, school, education and learning, behaviour, the local environment, community, money, attitudes and health), and these were organised into three domains (self, relationships and environment). Cross-cutting concepts were also identified: safety and stability, freedom, love, care and support, and fairness, respect and participation (Rees et al., 2009).

Overall, our review of existing domains in existing self-report measures and the Common Assessment Framework (CAF) identified 74 potential domains. In Appendix G the source surveys have been mapped by domain to allow identification and comparison of concepts that might be useful for this work. For example, activities, leisure and social networks are commonly included domains, although vary considerably: the KINDL\_R questionnaire for measuring health-related quality of life in children and adolescents focuses on everyday life activities; AUQUEI (the Pictured Child’s Quality of Life Self Questionnaire/ Autoquestionnaire de qualité de vie enfant image) looks at school and leisure; the Child Quality of Life questionnaire focuses on out of school activities; the Adolescent Wellbeing Scale asks whether adolescents enjoy the things they do as much as they used to; the Family Activity Scale asks about nine types of activity; the Young Lives Child Questionnaire includes ‘playing with friends’ in a question about what makes children happy. This exercise also usefully highlighted existing areas of overlap as well as the variety of ways in which common themes are operationalised. Of course, some of these 74 domains will be excluded from our list as they are unlikely to be influenced by children’s services.

While there is some consistency in selection of domains, the variation within domains is greater and has implications for the type of scaling that may be included in the CYPOC measure as it develops. Some domains may have only a neutral effect or elicit a reduced QOL (such as pain). Some service aspects are preventative, such as safeguarding. Soper and colleagues (2006) note it is difficult to measure something that does not occur as a result of services provided. Some domains assess only ill-being, rather than wellbeing and appear to assume that their absence equals the presence of wellbeing. This sort of assumption needs to be acknowledged and tested; the absence of high ill-being amongst adults has not been found to equal high wellbeing (Argle, 1996 in Davis et al., 2006).

### 4.3 Methodological and empirical issues

The literature review highlighted a number of methodological and empirical issues in measuring the outcomes of adult social care that are of relevance to children's services: the nature of outcomes, whether and how changes in welfare and wellbeing can be attributed to services, whether answer categories should focus on severity, frequency or both. Measuring outcomes in children's services raises a number of issues associated with the characteristics of the population and children's services. We need to consider: Outcomes for whom? How measures might take into consideration and be sensitive to cognitive development? Whether different measures are needed for different age groups to ensure age appropriateness? How measures might take into account response shift or age effects? Another challenge of relevance to children's outcomes is that while quality of care and quality of life are associated, there is not necessarily a causal relationship (Forder et al., 2007; Reed, 2007 cited in Forder, 2007).

If a measure is to capture outcomes that can be directly attributed to a service this has implications for other areas of data collection, particularly, the range of services used alongside the intervention under study. OPUS and some versions of ASCOT ask the adult service user whether services help in relation to each domain, as well as asking them to imagine what life would be like without services. Careful attention needs to be paid to research design in evaluating children's services to address complex issues of attribution of change (Soper et al., 2007).

In her review of generic paediatric quality of life measures, Stevens (2009) highlights three approaches taken towards scaling: the severity approach (used in the EQ-5D); a mainly frequency based approach (used in the SF-36); a mixture of both as used in the Health Utilities Index HUI 2/3. Stevens argues that each approach has limitations for a preference-based measure: the range of ways that someone is affected by an intervention may not be captured in a frequency-based scale, and frequency may not be adequately covered in a severity scale. The author suggests statement based severity scales probably offer advantages for preference based valuation (Stevens, 2009).

The use of parent-proxy reports for children's health-related quality of life questionnaires has been widely debated and may have relevance for administering the CYPOC measure. While self-report would be preferable, there is some evidence to suggest that children lack the cognitive and linguistic skills required to understand and respond to questionnaires about their HRQoL, or they may be too unwell to complete the questionnaire (Upton et al., 2008; Eiser and Morse, 2001). Converse findings show that children under the age of eight are able to use common response terms and use rating scales and that careful attention to how things are phrased enables them to understand and respond appropriately (Upton et al., 2008). Although there is value to obtaining proxy information,

... relying on an adult as informant may result in an incomplete assessment to the extent that the child's subjective experience and perceptions of HRQoL may be overlooked (Eiser and Morse, 2001 p 348).

In terms of instrument development and design, lengthy and complicated measures for self-completion by children and young people should obviously be avoided. Acquiescence response set bias is also likely amongst children - a tendency to choose the first answer option, provide repetitive responses, or extreme answers (Petrou, 2003; Matza et al., 2004). Children also have difficulties understanding negatively worded items (Matza et al., 2004). Some commentators advocate the use of pictures and

computer-generated administration to reduce the burden of measures and simplify completion. Self-report may require that developmental considerations be taken into account, for example

... it is a normal part of development for young people to minimise or deny risk or exaggerate their own competence in order to take on new skills or have new experiences (Department of Health, 2003b p 33).

Finally it may be that separate versions need to be developed for different age groups. Pavlovic and Leban (2009) found the importance children and young people placed on different areas of their lives varied by age group. They found that younger children were satisfied with feeling cared and provided for, while older aged children had developed a more abstract level of rights with an emphasis on autonomy, respect and influence on decision making. Response shift may also occur between age groups: the criteria people use to make judgements about their lives change over time, although conceptualisation of QOL has been found to be stable during adolescence in the absence of significant health threats (Gillison et al., 2008). Life satisfaction may decrease with age and potentially could be seen as a developmental phenomenon as well as an aspect of adolescents' wellbeing and functioning (Goldbeck et al., 2007).

## 5 Initial set of domains

Nine possible domains and definitions were identified from the literature and other instruments. These were reviewed within the team to ensure that they focused on areas of children and young people's lives that could be influenced by children's services. For this reason, some domains that affect children's wellbeing *per se* have been excluded: being healthy; economic or financial support/income (which is included in KIDSCREEN-52, 2004a); housing (part of the Common Assessment Framework) (The Children's Workforce Development Council, 2009); and life skills (such as shopping, cooking, money skills, using public transport).

The nine domains discussed, reviewed and developed in the focus groups were:

1. Physical care
2. Feeling safe and secure
3. School
4. Help and encouragement
5. Communicating
6. Feeling understood and being involved
7. Recreation and leisure
8. Relationships with family
9. Relationships with friends

An initial definition for each domain was developed to facilitate the focus group discussions and to identify initial areas of overlap or content that might warrant separation into new domains. This is listed below with some information about use of this domain in other outcome assessment scales.

### *Physical care*

*Physical needs, including enough healthy food and drink, warmth and shelter, clean and suitable clothing*

This 'physical care' domain mirrors the basic care domain of the Common Assessment Framework, which is located within the dimension of Parent/carer's capacity to meet the child's need. It can be considered a fundamental social care outcome.

In terms of the adult social care related outcomes framework it combines elements of three domains: Accommodation, cleanliness and comfort; food and nutrition; personal cleanliness and comfort. Food is included in other surveys, usually in terms of satisfaction with/enjoyment (Pavlovic and Leban, 2009) or whether children get enough food to eat (Young Lives, 2002).

This initial version set out to focus on provision and excludes activities of personal hygiene and personal care, such as washing, dressing and feeding oneself. The CAF covers personal hygiene under Self-care skills and Orientation, that is, it is within the responsibility of the child, and their development and functioning capacity.

The EQ-5D-Y covers self-care in terms of personal hygiene 1) looking after myself, defined as age-appropriate degree of independence in daily personal care covering washing and dressing but not activities such as feeding oneself, grooming and going to the toilet, and 2) washing self, defined as the ability to perform activities of personal hygiene (taking a bath/shower or brushing teeth) when compared to other (healthy) children of the same age and culture (Wille et al., 2010).

## **Feeling safe and secure**

*Feeling safe where you live and at school (free from fear of violence, physical harm, abuse, neglect, bullying and discrimination)*

There is scope to define a domain on safety in terms of location and hazards and dangers. In terms of location, it might focus on home, school and the local neighbourhood. It was decided from the outset to focus on home and school and not the local area. Home might include 'home' with birth parents and a foster home. The wording 'where you live' keeps the definition open to cover both. Future testing would need to explore whether 'where you live' is perceived as including the local area and neighbourhood. The exclusion of the local neighbourhood means that crime and anti-social behaviour are currently excluded. The rationale for this is that they are beyond the influence of children's services. The definition specifies being free from fear as the focus of the domain; it is intended to be about perceived safety and security and not limited to experiences of actual harm.

The ASCOT adult social care outcome domain on safety covers being free from fear of abuse, falling, or other physical harm and fear of being attacked or robbed (Netten et al., 2010).

## **School**

*Can go to school and get the help and support you need to do the best you can at school*

At the most basic level, the fundamental issue is whether children and young people have access to an education. All children have a right to an education (United Nations General Assembly, 1989) and the DCSF ECM framework includes attending and enjoying school.

It is intended that this domain pick up on the focus within children's services for help and support at school. Related issues might include whether children and young people have a quiet place to do their homework.

Young carers have reported wanting 'support at school together with allowances made for the pressure of their caring tasks' (Morgan, 2007 p 27)

The CRISP Children's Questionnaire also includes a school domain asking children whether they get the help needed in order to learn (Pavlovic and Leban, 2009).

## **Help and encouragement**

*Have help and emotional encouragement to deal with problems and pressures*

This domain combines elements from numerous sources: previous consultations with young people (Morgan, 2007), elements within the Common Assessment Framework (CAF; The Children's Workforce Development Council, 2009) such as parent/carer's capacity to provide emotional warmth, and an outcome domain identified in qualitative work with young carers relating to having encouragement and support (Holder et al., 2009). Guidance and support issues identified in previous consultations include help with problems and difficulties, and having someone to go to.

The domain is intended to cover whether children and young people feel they get the help and encouragement they need from adults, and might relate to parents, carers, social workers or support workers. The CAF for example, refers to carers providing support by recognising worries and anxieties, offering consolation, providing clear boundaries by making clear what they expect. Guidance and

support are linked to building self-confidence and feeling secure and able to deal with life's challenges and learn independence.

Previous consultations with young people identified getting help from adults when needed as important (Morgan, 2007). When children were asked about social workers, the top five types of help they said they received were: help with personal problems, listening, help staying safe, help getting ready to leave care, and speaking on the child's behalf (summary taken from Morgan, 2007). A report on running away also highlighted that children said they were less likely to run away if they had help with problems and pressures (Morgan, 2007). Young people identified various types of help that they like to see addressed or added to care plans:

- Building a young person's confidence – 'make the young person feel more secure, give them more help'
- Help with emotional difficulties and coping with the reasons for being in care, failing in education, or getting into trouble
- Where the young person can go for help for themselves when they need it – 'who to go to and who to contact' (Morgan, 2006 p17).

### **Communicating**

*Being able to communicate, have a say, and get the information you need to make decisions*

This domain reflects and directly maps onto the UN Children's Rights framework, specifically children's right to freedom of expression, to know what is going on and to access information concerning them (United Nations General Assembly, 1989). In their study of disabled children and young people's views about outcomes Beresford and colleagues (2009) found that 'being able to communicate' was identified as a fundamental outcome that influenced many other areas of life. The domain is intended to pick up on two-way communication, and to do so in relation to three elements:

- children and young people's perceived ability to communicate information to others;
- views about whether they are listened to;
- views about whether they receive or can get the information they need or want.

This domain is akin to a carer domain which was developed for the Kent Carers Survey around feeling skilled and informed, and which was revised and focused into a question about need for information, knowledge or training for caring.

In terms of links to existing instruments, one of the elements of communicating draws on the CRISP survey wording, which asks whether children are given the information they need to make decisions.

### **Feeling understood and being involved**

*Feeling understood and being involved by the people around you (treated fairly, able to make choices, able to follow own religion and that your views are taken into account and you are able to challenge decisions).*

The DCSF ECM framework refers to children being able to engage in decision-making. They also have the right to have their views taken into account in all matters affecting them (article 12, United Nations General Assembly, 1989). An American measure of health related quality of life of children undergoing

therapy for cancer looks at family dynamics and includes a question relating to fairness - whether parents treat them the same way they treat siblings (see Shanker et al., 2005).

This domain combines elements of two ASCOT domains: dignity and control over daily life. Clearly, children and young people have less autonomy, control and independence than adults. However, the UN Children's Rights framework emphasises that they have a right to have their views respected and to have their best interests considered (United Nations General Assembly, 1989).

### **Recreation and leisure**

*Enjoying the leisure and sports activities you want to do in your spare time, and doing them enough (in the afternoons, evenings and weekend, you can visit/see friends, go to the cinema, or to the park, go swimming, or skating or play football or netball, or go to dances, sports, special classes or clubs)*

Enjoying leisure and social activities in and out of school is widely recognised as important for children's development. It is included within the DCSF ECM fk and the UN children's rights frameworks. Currently, the proposed domain focuses on activities undertaken in children and young people's spare time; it does not specifically state school.

Consultations (Morgan, 2007) have highlighted the importance placed by young people on their ability to pursue hobbies and join groups. Young carers have reported missing out on after school activities, clubs and trips due to the practicalities of their caring roles, such as being responsible for taking siblings home after school (Holder et al., 2009). Recent qualitative research on parents' views on necessities for families with children, conducted as part of a review of government measures of deprivation for children, found that parents considered certain forms of leisure and social activity as necessities. These included having a bicycle, being able to swim regularly and to pursue a sporting, cultural or other interest in an organised way once a week (Hirsch, 2010 p150). Opportunities to take part in social activities, recreation and leisure are also an important element of social capital and linked to the wider environment and local area characteristics. The State of the Nation survey in Ireland asks whether there are good places in their area for young people to spend their free time (Office of the Minister for Children and Department of Health and Children, 2006).

Existing surveys tend to ask about opportunities or recent experience or current levels of participation in formal groups and associations. For example, the Organisation for Economic Co-operation and Development (OECD) Family Database Child Outcomes (2009) includes participation and membership data from the World Values Surveys from 2005-2007. These surveys asked young adults about group membership and intensity of participation, whether they belonged to groups of a particular type, and whether they considered themselves to be an active or inactive member of these groups. Groups identified included those based on religious affiliation, sports and cultural associations, organisations with a political orientation (including labour unions), charitable organisations and other groups (OECD, 2009b).

This domain also covers family activities, although other measures ask more detailed questions about the types of family activities. The Family Activity Scale, for example, specifies a range of activities which have fed into this domain (Cox and Bentovin, 2000).

## *Relationships with family*

*Enough contact with family members who care about you/are important to you and the type/quality of close relationships with family members you would like*

This domain aims to cover two aspects. First, whether children and young people have contact with the relatives they want to see and second whether the quality of these relationships is as they would want it to be. The current wording draws on the CRISP Children's Questionnaire (Pavlovic and Leban, 2009), which asks whether children are with people who love and care about them.

Children have the right to live in a family environment or alternative care, and to have contact with both parents wherever possible (United Nations General Assembly, 1989). The focus on children who use children's services means that there is potential for 'family' to be either foster carers and/or birth parents and siblings. Having a 'family' can be about continuing contact and the maintenance of relationships with a birth family (see Children Act 1989). However, this domain is defined in such a way that this duality does not matter; the focus is on being able to have relationships with parents, brothers, sisters, grandparents (relatives who are important to you) and the quality aspect might be interpreted both in relation to birth relatives and, say, foster carers.

The Health Behaviour in School Aged Children survey (HBSC) asks about ease of communication with mother and father as an indicator of close and supportive relationships (Currie et al., 2004; Currie et al., 2008), as does the State of the Nation's Children survey (Office of the Minister for Children and Department of Health and Children, 2006). Wellbeing at home, including time for talking with parents has been identified as a dimension of child wellbeing within the EU indicator set (European Commission, 2008 p 83).

This domain, along with the 'Relationships with friends' domain, is linked to the 'Recreation and leisure' domain. The latter focuses on whether children and young people do enough of the kinds of things they want to do (which might include family activities) and the former, focuses on whether they do these things with their choice of people.

## *Friends*

*Feeling you have enough friends, and friends who you feel are close/good/ care about you*

Relationships with peers are widely recognised as an important element of wellbeing, quality of life and child development. For example, close relationships support feelings of belonging and acceptance, and in turn identity and a positive self-image. The focus is intended to be on perceptions of having enough friends and satisfaction with the quality of those friendships.

In the ASCOT, this domain measures views about the sustenance of meaningful relationships with both family and friends (Netten, et al., 2010).

There is some overlap here in terms of relationships supporting feelings of being understood and involved. There is also potential for overlap with the leisure and activities domain.

## **6 Findings from the focus groups and proposed set of outcome domains**

The list of domains developed from reviewing the literature and existing instruments was discussed with children and young people in focus groups after they had first been asked to identify components or areas of life important to their wellbeing and quality of life. The discussions usefully provided examples of ways in which children and young people phrase and frame the issues we wanted to understand and showed that they needed to be worded in more child friendly ways.

Each group was fairly uniform in terms of age and stage in their life course and the education system. Their responses suggest that their concerns were very much grounded in their immediate experiences and everyday concerns. The pre- and young adolescent group included young people who had just moved schools and their discussion reflected their current preoccupation with making friends in school. Some of these participants were also receiving support to help them with such issues as making friends. The 'care leaver' group appeared to understand the topics of discussion very much from their own immediate standpoint of developing independence and taking responsibility for their lives. Within this group there was an emphasis on individual responsibility for their quality of life. They also spoke about being adults soon and having to be independent. The focus on their immediate situations suggests that designing the measure to focus on children and young people's immediate feelings and views, rather than defining a discrete recall period of one week, or one month for example, would be appropriate.

A few general issues were identified as relevant to all domains. First, consideration needs to be given as to whether instructions and question wording should specify or attribute each outcome area to particular adults and/or services. For example, that physical care is intended to relate to care provided by parents, foster carers and guardians, and similarly, which adults they might want consider when thinking about making choices, or engaging in decision-making. Another word of caution relates to the possibility that questions phrased in terms of aspirations or doing what you want, may be answered unrealistically or as one participant noted, we might get 'stupid' responses, such as carers not getting things right because they are not 'being bought a car or cigarettes or things they're not allowed'.

Analysis of the interviews suggested that some elements within the original domain set would be better as separate domains and some domains should have a narrower focus. There is uncertainty about the importance of some issues and these could be explored via further conceptual work, via further groups or cognitive testing. A few 'additional' issues were identified by the focus group participants that will require further exploration.

This next section describes the findings from the children and young people's responses to the open questions before highlighting findings taking each of the nine proposed domains in turn. Implications for changes to the conceptualisation of the domains or further work are highlighted wherever possible.

### **6.1 Responses to the open questions**

The children and young people's spontaneous responses to the open questions suggest that eight of our nine proposed domains are relevant and important, although a couple were only identified by the group consisting of older young people and some ideas represented partial aspects of our domains. Spontaneous remarks were made that corresponded to some degree to our domains of physical care, school, recreation and leisure, relationships with friends, relationships with family, and less commonly,

being involved and help and encouragement, and feeling safe and secure. Neither communicating nor getting the information you need was identified spontaneously.

Having fun, being happy and enjoying childhood were identified across the groups as important to their quality of life and wellbeing. A few issues not covered in our proposed domains were identified by the group of older boys: wearing 'decent' clothes and looking good; money; valuing your own life.

## **6.2 Views about the physical care domain**

*Initial definition: Physical needs, including enough healthy food and drink, warmth and shelter, clean and suitable clothing*

Participants' comments suggested that the term physical care is potentially misleading as it is associated with bodily health. Comments were made about being looked after if you are ill or have a condition such as asthma. Self-care in terms of looking after your personal hygiene (brushing your teeth, and keeping clean) was also mentioned, which was not our intention although this is covered in the EQ-5D-Y. Spontaneous remarks, however suggest that being looked after by your family is important. Needs in terms of eating, drinking, and sleep were spontaneously identified.

Participants highlighted the importance to children of satisfaction with food, and food as a source of enjoyment. Comments included 'When you're young you enjoy food quite a lot. I enjoyed eating' and 'I like my food'. One comment suggested that it would be unwise to phrase the question in terms of whether they get the food they like, as they might think about whether they get to eat 'steak every day for dinner'. Discussions about clothes among the older aged boys focused on image and the importance of this for their social life. An example was not wanting to go out wearing clothes bought from a supermarket.

*Implications for domain specification: The domain name needs to be changed or dropped in favour of only specific statements. It could include sleep. Understanding that we are focusing on the provision of basic care rather than self-care, would be aided by specifying who they might be receiving this from. The notion of adequate needs to be emphasised in relation to both clothing and food.*

## **6.3 Views about feeling safe and secure**

*Initial definition: Feeling safe where you live and at school (free from fear of violence, physical harm, abuse, neglect, bullying and discrimination)*

When asked about this domain it was generally agreed that it is important. However, there were differences between the groups' interpretation. The younger children talked first about their own personal behaviour, such as crossing the road safely with a lollipop lady, rather than external dangers. When they did talk about external threats, other than those posed by traffic, they talked about not feeling safe in their local neighbourhood. We had intended to exclude this location and to focus on school and where participants live. The other two groups mentioned home, school, and more specifically, in the playgrounds, and outside school as places where they wanted to feel safe. One participant noted the possibility of violence at home from parents or foster parents. The teenage boys said fighting in town was a problem for them and they wanted to go to places without worry.

*Implications for domain specification: The domain needs careful framing to ensure children and young people focus on the required locations, and these need to be decided.*

## 6.4 Views about school

*Initial definition: Can go to school and get the help and support you need to do the best you can at school*

There was general agreement that going to school per se is important in terms of learning and getting an education. Being able to go to school and do the best you can was our intended focus. However, the participants' discussion highlighted that feelings about school can be negative, positive or ambiguous. Some of the girls' comments suggested that the way they felt about school was strongly linked to whether they had any friends at school. A girl who said she did not have any friends, said she was 'all lonely, so I don't care for school anymore'. The teenage boys suggested that views about the value of school differ with age; now he was older one boy said he wished he could go back to school and 'get better grades' as it was 'the best thing for me'. This participant suggested that if you ask children about school a negative response is likely: 'you're going to get "school sucks. It's just boring."

*Implications for domain specification: The focus groups highlighted the overlap between this domain and the next focusing on help and encouragement. The school domain could be revised to focus on whether children and young people feel that they can go to school and take part in learning so that they can achieve the best that they can (without a specific emphasis on help and support, which would be covered in the separate help and support domain). The response categories could be worded in such a way that the options pinpoint whether sufficient help and support are received to do the best they can.*

## 6.5 Views about help and encouragement

*Initial definition: Have help and emotional encouragement to deal with problems and pressures*

There was general agreement that this domain is relevant and important, something that children and young people need. The domain was intended to focus on help and support with personal problems and pressures beyond problems at school that might be provided by parents, carers, social workers or support workers. This focus would need to be made explicit in the question wording. Alternatively, given the issue highlighted in relation to the 'school' domain, and the people participants identified as sources of help (see below), this question might better encompass help and encouragement more widely. Young people did not make such distinction when providing examples of help and encouragement. These included help with making friends, encouragement to follow your dreams, to do well in your subjects at school, and to do your homework. When asked who they might get it from participants identified parents, teachers, family, friends, foster carers, counsellors, school support officers. Being supported in decisions was also raised as important. This type of support could be included here or within the domain trying to capture whether their views are taken into account (see below).

A caveat noted by one of the teenage boys is that 'no-one wants school helping' as 'you're going to feel singled out and like they're treating you differently. It's not good – especially if it's just because you're in care'. Help in relation to special needs such as autism or dyslexia was identified as separate to help linked to being in care.

*Implications for domain specification: The definition of the help and encouragement domain could be broadened to cover help from adults at school. The wording of the question and response categories needs to pay attention to the possibility that children might not want help at school. Wording that*

*focuses on help that you need to do well at school and more generally to be confident, and deal with difficulties or personal problems could be taken forward. For example, help and encouragement to be confident, to make friends, to do well at school and to deal with problems and pressures.*

## **6.6 Views about communicating**

*Initial definition: Being able to communicate, have a say, and get the information you need to make decisions*

The term communicating was not easily understood. Within the groups the researcher started to use the term two-way communication to try to get at the issues intended. This did not solve the problem. The term communication appeared to conjure up ways of communicating, such as using mobile phones. However, in the discussions certain aspects were identified as important that mirror elements of findings from the literature review: 'getting their say' and 'having a chance... to say what you want to say' to parents; 'being able to be vocal about your opinions'; being able to talk to friends and develop social skills. In the group including young people whose first language was not English, communicating was seen in more basic terms, to be accepted, to make friends and to get a job. This group also spoke of the importance of being able to express yourself and your feelings. Self-expression was valued in itself and as an important pre-cursor of being listened to.

None of the group participants brought up information provision. When asked directly what sort of information they might want or need the children were able to suggest some things but these were relatively vague and did not relate to information they ever asked for or wanted: information on your wellbeing; how to live your life right. This element of the intended domain was relatively under-explored in the groups and so we are as yet uncertain if it is relevant or important.

*Implications for domain specification: The Communication domain would be more easily understood if it focused on being willing and able to have your say (this could cover confidence and issues related to communication difficulties), which should cover whether adults give children the chance to have a say. The definition could also include being able to challenge decisions (originally included in the 'being involved domain' (see below). Further work might explore whether this domain should cover communicating with other adults as well as parents. It would also be useful to explore further whether there is a need for a domain about getting information. It may be that this issue can be dropped or should be a separate domain that is more concrete and focuses on whether children and young people get information that helps them make decisions (see the CRISP questionnaire).*

## **6.7 Views about feeling understood and being involved**

*Initial definition: Feeling understood and being involved by the people around you (treated fairly, able to make choices, able to follow own religion and that your views are taken into account and you are able to challenge decisions).*

The participants' comments suggest that the general terms 'feeling understood' and 'being involved' are likely to be understood in relation to friends rather than adults. The younger children living with their families, and the group of looked after children and young people spoke of wanting to be involved in activities, games and discussions with school friends, and not being 'left out'. However, some of the elements outlined in our initial definitions for this domain were identified by the children and young people. For example, parents letting them have a choice about what they do, such as when they go

out, parents and foster carers involving you in things within family life and 'bring(ing) you up kind of more involved, more talkative, easier to make friends, easier to do everything'. This comment, however, also shows the close links between the quality of relationships within families, the support and encouragement provided and the sense of being involved. One boy spoke of how being involved helps him 'feel you are someone in the world and you exist'.

*Implications for domain specification: The domain could be defined so as to focus more specifically on adults allowing children and young people to make choices, and whether they feel adults take their views into account. The focus on feeling involved could be picked up elsewhere, such as within the friends and family domains. As noted above, the element in our original description focusing on being able to challenge decisions could be included with the communication domain, which focuses on having a voice. Being listened to and being able to challenge something, however, is not the same as having your views taken into account. This domain, although closely linked to the 'Communicating' domain and 'having a say' is intended to capture children and young people's ability to have an influence, impact and choice. Measures concerned with adults social care related outcomes ask about choice and control. Children and young people have less choice and control in their lives but this domain would attempt to capture whether they have a degree of autonomy and influence. The following re-focused and re-worded definition could be taken forward: Choice and influence: Feeling that your views are respected and taken into account by adults, and that you are able to make choices and influence decisions that concern you and what you do.*

## **6.8 Views about recreation and leisure**

*Initial definition: Enjoying the leisure and sports activities you want to do in your spare time, and doing them enough (in the afternoons, evenings and weekend you can visit/see friends, go to the cinema, or to the park, go swimming, or skating or play football or netball, or go to dances, sports, special classes or clubs)*

As anticipated, the terms recreation and leisure are unfriendly and risk being interpreted narrowly in terms of outdoor pursuits. This may be due to 'recreation' being linked to sports and recreation grounds. The younger children highlighted the importance of just being able to go out and play. Many activities, sports and hobbies were identified as desirable by the focus group participants: playing, swimming, running, football, basketball, cricket, rugby, hockey, going out with your family, going to the beach, snooker, pool, dancing, reading, watching television, walking the dog, going to school clubs (such as drama or choir). A few children highlighted the importance of having your 'own time', time to 'be on your own sometimes', 'time to get away from everything'.

*Implications for domain specification: The coverage of the domain should be expanded to include having time to be on your own when you want to. The wording of the domain could focus on having enough time to do the things you want to do after school and at the weekends. It would be useful to test different examples to ensure that less structured and less organised activities such as playing, watching television and having time to yourself are included.*

## **6.9 Relationships with family and relationships with friends**

*Initial definition regarding family: Enough contact with family members who care about you/are important to you and the type/quality of close relationships with family members you would like*

*Initial definition regarding friends: Feeling you have enough friends, and friends who you feel are close/good/ care about you*

Both these domains were identified as relevant and important. 'Mum' or siblings were often identified as the most important things in the children and young people's lives. The participants spoke of the importance of spending time with family. However, the desirable qualities of relationships with family were relatively under-explored in the groups. The domain was one of the last of a relatively long list and its relevance had always been established earlier in the groups in relation to the open questions. Disliked aspects of relationships within foster families were highlighted in one group by someone who spoke of wanting to be treated the same as their own children.

Relationships with friends in terms of having friends and spending time with them was identified as very important across all of the groups. One of the teenage boys noted the importance of spending time with his girlfriend. Girlfriends and boyfriends had not been included in the original definition. Some of the children spoke of the desirable qualities of friendships; it is important to children and young people to have friends who will 'be with you no matter what' and who will 'help you through tough times'.

*Implications for domain specification: The conceptualisation of these two domains appears to be both relevant and important. Further work to test the wording of the definition is required, perhaps to be phrased as 'enough contact with'.*

## 7 Conclusion

This short piece of work aimed to identify domains that could be used in a self-report (subjective) measure with which *final outcomes* could be assessed as part of a micro or user-level cost-effectiveness evaluation. Final outcomes are defined as the changes in wellbeing (broadly defined) of children and young people in response to particular service or intervention. Economic evaluations require a standardised, quantitative measure of outcomes, ideally one that can be combined into a single figure. We do not discuss the implications of such an investigation for research design but the minimum requirement would be a comparative study with measures pre- and post-intervention.

We identified a number of practical challenges in reaching the population – children in receipt of services – for whom the final CYPOC would be relevant. To develop the measure fully, we need to speak to more children in different circumstances. We also identified challenges for the future in terms of the design of the questionnaire. For example, the desire to be able to measure the same thing across different services needs to be balanced by the need for specificity in the way questions are asked so that children and young people fully understand the questions. Similarly, the literature suggests that developmental stages may mean different versions of the questionnaire are necessary, although this could not be assessed here. The children and young people – although just a small group – highlighted the importance of the language used both in the questions and the potential responses, and identified links between the domains. The focus groups also showed that children and young people responded in terms of their immediate situations, feelings and views.

A range of literature guided selection of the initial domains, including policy-related frameworks, collections of outcome indicators, and existing measures used in health economics, and evaluations of adult social care, and children's health and social care. We identified nine domains that were commonly used and which were also likely to be influenced by children's services. This work and the subsequent discussions with children and young people suggest that the following quality of life domains should be taken forward. Currently, the list is in no particular sequence, although some relate to areas of life where a low score might indicate a level of unmet need that constitutes an unacceptable risk to children's health or safety.

- ***Provision for physical needs, including food and drink, warmth and shelter, clean and adequate clothing.*** The domain requires further conceptual development and re-wording.
- ***Feeling safe and secure*** Care is needed to ensure that respondents focus on the threats and hazards intended. The current intention to exclude neighbourhood from the domain is open to debate. If it is desirable to develop a measure that captures information about children and young people's views about feeling safe and secure in their local areas, walking to and from school etc., then it might be possible to develop another version of the domain or an optional add-on domain.
- ***Whether children and young people can go to school and do the best that they can.***
- ***Receipt of help and encouragement to be confident, to make friends, to do well at school and to deal with problems and pressures.*** This should cover help from teachers as well as parents, carers, social workers, support workers.

- *Being able to express yourself, being given the opportunity to have your say and being able to challenge decisions by adults, such as parent* This could cover confidence and issues related to communication difficulties.
- *Being listened to, able to make choices and have your views taken into account*
- *Having enough time to do the things you want to do after school and at the weekend.* (To include examples of sports, hobbies etc.)
- *Spending enough time with family who are important to children and young people.*
- *Spending enough time with friends who are important to children and young people.*

For some time there has been increasing emphasis on measuring outcomes in public policy, practice, regulation, and the monitoring of performance across education, health, social policy and children's services. It is a fast moving field and policy developments since the work for this report was carried out suggest that there is an ongoing and urgent need for local authorities to understand what produces high quality services, how services impact on the children who use them, and how well the needs of children are being met. Frank Field recently emphasised the need for local authorities to draw on and develop a strong evidence base and to evaluate new services robustly (Field, 2010). The Coalition government is promoting the use of wellbeing measures to monitor public policy progress and as an indicator alongside economic growth (HM Government, 2010, Prime Minister, 2010). The Deputy Prime Minister has recently stated that he believes a society should be judged on 'how it treats its children' (Deputy Prime Minister, 2010). Ensuring services focus on supporting the neediest families, help families with multiple problems, and provide support to those under greatest pressure are linked to the promotion of a fairer society. The creation of the new rights based Children's Commissioner for England signals a further commitment to promoting the effective participation of children in services that affect their lives and upholding the United Nations Convention on the Rights of the Child. The establishment of the new Childhood and Families Task Force also signals the importance being placed on identifying policies that make the biggest difference to the lives of children. The value of monitoring the subjective wellbeing of children over time is also being increasingly recognised within wider debates about how to conceptualise child poverty and there has already been a move towards the consideration of factors that are broader than material well-being, including the children's rights, relationships and subjective wellbeing (Bradshaw and Keung, 2010, Pickett and Wilkinson, 2007, Unicef Innocenti Research Centre, 2007).

## 8 Proposed next steps

Further qualitative work would be needed to develop a measure, with the following aims:

- To confirm and refine the number and content of the domains to maintain our focus on the areas on which a service might have an effect.
- To refine the wording so that allusions to children's services are understood.
- To discuss these domains with a larger sample of children who have experience of children's services, stratifying samples by gender, age, type of service received.
- To develop the domains into a set of questions with appropriate scaling, question wording and instructions.
- To conduct a small pilot study and cognitive testing to refine the questions and assess whether it is practicable for children and young people to understand and complete the measure themselves. In particular we need to ensure that it is not too long and over-burdensome, and that children can understand the terminology, read the instructions, follow the format and that they find the response options relevant and discrete.
- To assess the content and face validity of the measure.
- To establish whether the measure can be used across client groups, interventions and services.
- To explore whether different versions of the CYPOC measure would be needed for young and older age groups.

Addressing the last two aims would require involving a wider range of children and young people to ensure coverage of different sections of the population of users of children's services. A small period of feasibility work would be sensible to identify how a purposive sample might best be achieved and recruited given the challenges of accessing sampling frames in this work. This might involve care service provider organisations, or schools and councils.

In the longer term a quantitative study is needed to conduct the psychometric testing, perhaps using the questionnaire within a large study and alongside other outcome schedules. These data sets can be used to explore validity from a theoretical and statistical standpoint.

The long term aim of this work is to develop a preference based measure for use in economic evaluations of children's services. Tasks for the future therefore are to assess the feasibility of generating preference weights from the CPYPOC response options, select an appropriate method and undertake a large-scale preference study. Responses will be aggregated to provide the preference weights so participants' "CYPOC profiles" can be converted into a single index. There are various techniques for eliciting preferences and it is likely that either discrete choice experiments or best/worst scaling methods will be used (these were found to be most appropriate in the ASCOT measure). We would aim to include children in need, their supported peers, and adults (as funders of care system). The data from these three populations may lead to different weights for each domain and a clear strategy would be required for dealing with this.

The final test of the measure is to use the data from the interviews and the preference weights (potentially those derived from all three populations) to calculate one (or more) single index of change in wellbeing – the outcome – that is the effect of the intervention(s) and support used and undertake cost-effectiveness analyses.

There is no doubt that the work required to develop the CYPOC measure fully is complex. Significant progress has been made in this study in terms of reviewing the relevant literature, and identifying a set of domains that describe areas of children's lives that could be influenced by the services and supports they receive. There is much work still to do and although we can build on previous research at the PSSRU and within health economics, it will take a considerable amount of time. The benefits of such investment in research are enormous as it has the potential to generate improvements in the way scarce resources for children's services are spent through the provision of high quality evidence on the cost-effectiveness of existing and new services and supports for children and families.

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## Appendix A Questions, types of economic evaluations, and utility measures

This Appendix identifies the types of research that the CYPOC, used within the context of economic evaluation, would address. The research has taken the first steps towards developing a generic standardised schedule that can assess the outcomes generated by children's services within quality of life domains that are supported by the literature, acknowledged as important by children and young people, and reflect aspects of children's lives that services may be able to influence. It is intended to be used in micro-level economic evaluations. Such evaluations can provide information for policy-makers and commissioners as they decide how best to respond to the young people's needs within limited resources. In the next section, five generic questions are identified with examples relevant to children's services.

The central concept of such evaluations is *efficiency*, that is, a statement or measure of the achievements of a particular service and the resources and other factors that combine to secure them. The most commonly used 'efficiency analyses' are described in the subsequent section; cost effectiveness analysis, cost utility analysis, cost consequences analysis and cost benefit analysis.

It is very difficult at this stage to describe what the final CYPOC measure will look like. We have so far only identified the domains of interest and there is still a considerable amount of work to develop the work to date into a research instrument. In the final section of this appendix we have illustrated how one of the more common measures of health-related quality of life works both as a measure of health status and as a single index of outcome for use in economic evaluations.

### Questions addressed

Efficiency analyses as defined above can generate the information needed for a variety of decisions which can be summarised in five deceptively simple questions (Beecham and Knapp, 1995; Knapp and Beecham, 2010).

- What intervention (programme of support, service, etc) is more or most appropriate in given circumstances?

The classic illustration of this question is economic evaluation of pharmaceuticals – is this drug a more cost-effective treatment for Condition A than another drug? For children's services, the question might concern, say, different types of parenting programmes; will the Incredible Years programme or Strengthening Families or perhaps a locally developed programme provide better outcomes at lower costs. Or would a neighbourhood or community programme work equally well at less cost? Compared to the level of 'what' decisions practitioners in children's services face every day, the evidence base on which to draw information about costs and effectiveness is tiny.

- When should the intervention be provided?

This question is particularly relevant in today's policy environment where the focus has turned to early intervention as a means of preventing later problems in (young) adulthood. Assessing the impact of early intervention is difficult because so many of the impacts of such programmes may be a) things that *don't* happen, for example, behaviour does not deteriorate and b) likely to happen quite far into the future, requiring an investment into longer-term longitudinal research. Another example of a 'when' question is faced by many social workers; at what point during family support where abuse is suspected should the service consider starting care proceedings?

- Where should it be provided?

The location of support is an important question; should parents attend an appointment in the practitioner's office or should the practitioner call at the family's home? Another unresolved question is about the extent to which looked after children should be placed in residential care or foster care. The policy emphasis has for many years been on providing foster care, but for some children this may not be the most cost-effective location. Indeed, intensive forms of foster care, where treatment and high levels of additional support are provided, can be a more expensive but potentially more effective option for some children and young people.

- To whom should it be provided?

The 'to whom' questions are important to priority setting exercises and day-to-day practice. A recent example in the news concerns the seasonal 'flu jab. Current policy is that only individuals who are at risk of serious complications from 'flu are eligible; normally healthy children do not routinely receive the jab. Key worker services and transition support are topics for which this 'to whom' question is highly relevant. Indications of the likely importance of this question can be found in almost any study. Most will show variation about the mean on almost every cost or outcome measure suggesting markedly different responses within groups.

- How should it be provided?

This question is closely related to the other four but focuses on the way care is organised, rather more than where it is sited or who will use it. Personal health and care budgets are a prime example. Will self-directed care provide a more appropriate and more cost-effective way of supporting disabled children and their families? Other questions might concern the relative cost-effectiveness of organising services through Sure Start or Family Centres rather than through their separate provider agencies, or forming combined departments in local authorities or health trusts for children's services.

The sixth generic question is 'why'. Why is this intervention (programme of support, service, etc) more cost-effective than another? Why do some ostensibly similar services work better for some than for others and cost different amounts? Simple average results are not sufficient to address this question. Work is required to unpack aggregated findings and to look carefully at the 'black box' that links inputs with outputs, and costs with effectiveness. We need to know not only *what works* but also *why*. We need more economic evaluations of children's services, but we also need *better* ones.

### **Types of economic evaluation**

Box A.1 briefly defines four common types of economic evaluation; cost effectiveness analysis, cost utility analysis, cost consequences analysis, and cost benefit analysis. We have omitted from this box analyses that involve costs but not final outcomes as they are not, within the tenets of economic theory, economic evaluation. These cost analyses tend to be of two broad types.

- A simple *cost comparison* which compares the costs of two or more services to identify which is the less expensive, or compares the set of services (summarised as costs) used by one group who also receive a particular intervention with the set of services used by a comparison group.

- A *cost savings analysis* which compares two or more services (or a service and no service) to identify which will save more money. These studies address questions such as ‘if you implement Intervention A, what savings will accrue in the future to a particular provider or the public purse?’ They may look at down-stream savings within a year, or much further ahead, perhaps 5, 10 or more years into the future. Commonly these use *intermediate* (service-related) outcomes such as the monetary value of a change in the amount of services used, or perhaps employment status or income level for longer-term studies. These studies are often misnamed cost-benefit analyses.

Box A.1, therefore, focuses on types of studies that combine costs and final outcomes. None of these types of analysis are common for children’s services. In part this is because – in comparison to adult health or mental health care – it has taken a long time for cost issues to be considered within children’s services’ research. But also it is in part because the designs required for economic evaluation are more akin to those used in medical or clinical research and are rarer in studies of children’s services. We do not address research design requirements to any great extent in this report, but cost-effectiveness is a *relative* concept – is this service more (or less) cost-effective than another? Thus a comparative design is needed to show that the impact of one service is greater than the impact of another. In turn this implies that a measure of change over time is also required; before and after the intervention or service is likely to have an impact. Economic evaluation also requires quite large sample sizes otherwise the skew in the costs data leads to invalid statistical results. (In most studies, the distribution of costs shows that many people have relatively low costs – that is, they use a relatively low level of services – and only a few use services intensively leading to higher costs.)

What differentiates each type of evaluation in Box A.1 is the treatment of outcomes. Importantly this has implications for the type of information most useful to a policy maker or commissioner in a given situation. For example

- A cost-consequences analysis will provide detailed information on the outcomes generated by the intervention across a whole range of aspects, which may well reflect the range of intended impacts of the service. Such findings provide a very good picture of what the service can achieve. However the findings are complex to interpret and it can be difficult to prioritise the results, particularly where the cost-outcome associations go in different directions.
- A single outcome cost-effectiveness analysis provides a simple measure of how much it costs to obtain an additional unit of outcome; the results are easy to present to busy decision-makers. Where the same instrument has been used, this ratio of costs and outcomes can be compared across studies. However, most instruments are very specific and it is rare for different evaluations of the same service/intervention to use the same research instruments. It is even rarer for evaluations of different services to use the same instrument thus making it very difficult to compare findings across different services.
- A cost utility analysis aims to overcome these two challenges as it employs an instrument that is sufficiently generic to be used across a variety of services, and one that is based in population preferences for different mixes of aspects of quality of life rather than direct measures of functioning, behaviour, attitudes and the like. The findings can be presented as a

description of levels of quality of life, or be 'converted' to a single index (scored, for example from 0 to 1) which can be used to show the relationship between outcomes gained and the cost of achieving them.

### **Box A.1 Types of economic evaluation**

#### ***Cost effectiveness analysis***

A single measure of outcome is used and the ratio between costs and effectiveness (cost per one unit of improvement) is often calculated as an ICER, an incremental cost-effectiveness ratio. This might be, for example, the cost of a one point reduction on a specific research instrument measuring mental health, perhaps the Strength and Difficulties Questionnaire in the case of children's services, or the additional proportion of children no longer considered a 'clinical case'. Most such research instruments are specific to the condition or context being evaluated so it is difficult to make comparisons between different studies.

#### ***Cost utility analysis***

This can be thought of as a special category of cost effectiveness analysis that uses a generic (that is, applicable in many contexts) instrument that assesses 'utility'. In UK health care evaluations, a commonly used utility measure is the Quality Adjusted Life Year to obtain a measure of health-related quality of life (HRQOL; [www.euroqol.org](http://www.euroqol.org)). Here the utility measure captures individuals' preferences for 'health states' each of which represents a different combination of life expectancy and aspects of quality of life. Thus, by combining QALY data with cost information a cost-per-QALY-gained for a specified intervention (in comparison to another or no intervention) can be calculated. For adult services, there is a measure to assess social-care-related quality of life (SCRQOL, [www.pssru.ac.uk/ascot](http://www.pssru.ac.uk/ascot)). While there is a youth version to assess HRQOL there is no equivalent for the broader range of children's services.

#### ***Cost consequences analysis***

Commonly in evaluations of children's services a range of outcome measure are used, perhaps including schedules to assess (change in) behaviour, attitudes, self-confidence or relationships with family and peers. Some of these schedules will be standardised and have had extensive psychometric testing, others will have been specially designed for each study. In a cost consequences analysis, several outcome measures will be assessed alongside costs, often employing multi-variate analysis. While such analyses can more closely reflect the multiple aims to be found for children's services, they have the disadvantage of providing results that are less clear cut; it is not uncommon to find that while greater improvements in one outcome area are associated with higher costs, another may have a negative association with costs.

#### ***Cost benefit analysis***

In this type of analysis costs and outcome are valued in the same metric. As with the other three forms of economic evaluation, it is *final outcomes* (changes in health and welfare) that are of interest. A cost benefit analysis, therefore, would require such an outcome (perhaps an improvement in behaviour or positive change in attitudes) to be valued in monetary terms. Some studies assume a link between final outcomes and an intermediate measure (perhaps reduction in services used) which can be more easily valued in monetary terms; this is a cost-savings analysis. Willingness to pay methods are being developed to obtain a monetary value for a final outcome. Their application in children's services is extremely rare.

Adapted from Beecham, J., and Sinclair, I. (2007) *Costs and Outcomes in Children's Social Care: Messages from Research*, Jessica Kingsley, London, p38-39.

### **How a utility measure might work; the EQ-5D and the ASCOT**

The EQ-5D is a short questionnaire that can be completed in 5 minutes or so. There is a simple visual analogue scale asking participants to score their overall health status on a scale of 0 to 100 in response to the following prompt

- Think about how good or bad your own health is today... The best health you can imagine is marked 100 and the worst health you can imagine is marked 0.

The central part of the questionnaire is five questions asking participants about their mobility, self-care, usual activities pain/discomfort, and anxiety/depression. There are three possible responses for each question following a similar pattern as the ones below for mobility

- I have no problems walking about (scoring 1)
- I have some problems walking about (scoring 2)
- I am confined to bed (scoring 3)

From these five questions a numerical profile can be built up for any participant. Someone who has no problems walking about or with self-care activities, has some problems performing their usual activities, is in extreme pain or discomfort, and who is moderately anxious or depressed would have a composite score of 11232. These descriptive data can also be used to show the health status of a population by listing the different areas and calculating the proportion who, say, have no difficulties in each area.

The combination of all the options gives 243 possible health states (combinations of different statements) plus 'unconscious' and 'dead'. Using data from a large survey, population preferences for these health states were estimated and given weights of between 0.00 (dead) and 1.0 (perfect health). The survey used a 'time trade off' approach, asking the survey participants to 'trade' years of life for different health states. The first and second columns of the table below show the score for a combination of responses on the EQ-5D. The final column shows the utility value attached to each health states from the population survey.

EQ-5D score	Description	Utility weight
11111	Mobility – no problems. Self-care – no problems. Usual activities – no problems. Pain/discomfort – no problems. Anxiety depression – no problems.	1.00
21121	Mobility – some problems. Self-care – no problems. Usual activities – no problems. Pain/discomfort – some problems. Anxiety depression – no problems.	0.727
11223	Mobility – no problems. Self-care – no problems. Usual activities – some problems. Pain/discomfort – some problems. Anxiety depression – major problems.	0.255

Thus from the EQ-5D questionnaire can a single index be generated that combines the specific 'health states' of individuals in the study with population preferences for those health states. The change in the utility weight is derived from the score post-intervention minus the score pre-intervention. This is the QALY gain – most commonly estimated as the average additional gain over that derived by the comparison groups that did not receive the intervention under study. Resource use data are collected alongside the EQ-5D to provide information on the costs required to achieve that QALY gain.

The Adult Social Care Outcome Toolkit (ASCOT; [www.pssru.ac.uk/ascot](http://www.pssru.ac.uk/ascot)) takes a slightly different conceptual approach. The Toolkit is based on the concept of *capacity for benefit* (CfB) aiming to distinguish what services could provide from what is provided in practice. Thus CfB is the level of well-being that could be delivered by the service(s), assuming perfect service quality and taking into account the characteristics and needs of service users. The central part of the schedule comprises eight or nine domains (depending on the service under study), again linked to aspects of quality of life that services can influence: personal dignity and comfort; social participation and involvement; control over daily life; meals and nutrition; safety; accommodation cleanliness, order and accessibility; employment and

occupation; role support; and living in your own home. Each of the domains is scored by (or for) participants in terms of their needs to be met along each of the domains; no need, all needs met, low level of needs, high level of needs.

As with the EQ-5D, this research has involved a large survey to identify population preferences. For the ASCOT, this was to assess preferences between all possible scenarios of (met) needs for all the domains using a discrete choice approach to balance the scenarios with money. The resulting monetary values represent people's 'willingness to accept' financial compensation for changes between the (met) needs states.

Both the ASCOT and EQ-5D have some relevance for taking forward the CYPOC. Similar methods were used to identify and confirm the domains and both the EQ-5D and the ASCOT are generic instruments which can be used across many different types of services and are based on quality of life domains that can be influenced by services. An important difference is that the EQ-5D aims to measure changes in health status directly whereas the ASCOT asks whether certain needs are met. Both studies have used a population survey to estimate preferences for the different 'quality of life states'; the EQ-5D aims to assess the cost of achieving health gains that incorporate quality and quantity of life, the ASCOT uses the more easily understandable best-worst scenarios to value changes in quality of life directly. Although its final format is yet undetermined, the most likely approach for the CYPOC in terms of the response set and preference survey would be closer to the ASCOT because children's services tend not to address length of life.

## **Appendix B Research in progress**

This appendix highlights research in progress or about to be published on measuring child outcomes and well-being as identified between April 2010 and September 2010.

### **Qualitative research developing understanding of children's subjective wellbeing**

Dr J Rahi at the Institute of Health, University of Warwick, is developing a vision-related subjective quality of life outcome (VRQOL) instrument for self-completion by children (CERUK).

The Family and Parenting Institute is exploring two issues in wellbeing: *Can government measure family wellbeing?* and *Measuring the capability of physical wellbeing for British children*. Reports will be published later this year although it is not clear whether this is qualitative or quantitative work:

<http://www.familyandparenting.org/currentResearch> Accessed 12/07/2010.

The National Children's Bureau and London Metropolitan University are exploring wellbeing in early childhood (cited in Statham and Chase, 2010)

National Philanthropy Capital (NPC) is developing a wellbeing tool for use by charities and schools, to show their impact on the wellbeing of young people aged 11 to 16. It will be available online late in 2010. The tool assesses seven aspects of young people's subjective wellbeing: self-esteem, resilience, emotional health, quality of relationships with peers, quality of relationships with family, satisfaction with school, and satisfaction with community. Barnardo's, Beatbullying, The Outward Bound Trust, The Place2Be and The Prince's Trust have already piloted the measure.

### **National surveys that include wellbeing or outcome measures**

The annual Scottish Health Survey includes the Warwick Edinburgh Mental Well-being Scale (WEMWBS), which has been validated with 13 and 15 year olds (Thompson and Aked, 2009).

### **International surveys of poverty and wellbeing**

An international study of childhood poverty is being conducted at Oxford University; 12,000 children in four developing countries are being tracked over 15 years to see how poverty affects their wellbeing. Children and carers are surveyed every three years: [www.younglives.org.uk](http://www.younglives.org.uk)

The World Health Organization's cross-national Health Behaviour in School-aged Children Survey (HBSC) uses the school class as a sampling unit. It is an international survey conducted in collaboration with the WHO Regional Office for Europe and is conducted every 4 years. There is a growing international network of participating countries.

## APPENDIX C

### The Research Team

The research team includes Ketta Holder, Emily Knapp and Jennifer Beecham

### How to find out more

Information and examples of our work can be found at:  
<http://www.PSSRU.ac.uk>

If you have any questions, please get in touch with me, Ketta Holder

Telephone: 01227 827587

Email: [J.M.Holder@kent.ac.uk](mailto:J.M.Holder@kent.ac.uk)

Address: PSSRU

University of Kent

Cornwallis Building

Canterbury

Kent CT2 7NF

Outcome Measure of Child Wellbeing,  
Summer 2010

## Children and Young People: What do you want from services?

Be valued

Have a say and a  
choice

Be safe

Help with...

## **Who are we?**

We are researchers at the University of Kent and are doing some research for the Government's Department for Education.

## **The main reason for the research**

We want to talk to young people between 11 and 16 years old who have used children's services. We want to find out what is important to you and your quality of life, especially the areas of life children's services can help. We want to develop a list of 'outcomes' for young people who use children's services and to say what these should cover.

## **How can you help?**

We'd like to talk to about 15-20 young people in small groups. The discussions will last about one hour and be held locally. We'll arrange a day and place and let you know.

If you agree, we'll record the discussion so we don't miss anything. All information will be treated in the strictest confidence and kept securely. We will not give anyone's name in reports or when we talk to people. No-one will be able to trace any information back to you.

We will talk to you about

- ⇒ What areas of life are important to your wellbeing (like friendship or feeling safe) and can be helped by children's services?
- ⇒ How you would like your life to be in these areas?
- ⇒ What you want children's services to help you do and feel?

## **Your rights when taking part**

- ⇒ You don't have to take part, it is up to you.
- ⇒ You don't have to talk about something if you don't want to.
- ⇒ You can leave the meeting at any time.
- ⇒ If someone says they are at risk of harm, we'll tell someone who can help.

## **What will happen to the information?**

We will write a report for the Department for Education and a summary for those who took part.

The information will be used to help develop a research questionnaire to see if young people think they get any benefit from the services they use. This should help people in local and national government see what works and decide what to spend money on, and help young people get useful services.

## **If you want to help...**

Kent's Children in Care Council have welcomed this project as a useful piece of research. If you want to help please:

- 1) Fill in the **Children and Young People's Reply Form**
- 2) Ask your parent or guardian to fill in the **Parent's Form**
- 3) Please return **both** forms to \_\_\_\_\_.



## Children and Young People's Reply Form

If you want to take part in the group discussion about areas of your life that are important to your wellbeing and what children and young people want from support and services, please complete this form in BLOCK CAPITALS and return it to \_\_\_\_\_.

What is your name?.....

What is your telephone number?.....

- I would like to take part in the group discussion with other children and young people and researchers

Your signature.....

Today's date.....

If you would be happy to be contacted again to be asked to take part in more research on this subject please write your address below so that we may contact you again.

Address.....

Postcode.....

Please give this form to your \_\_\_\_\_.

### Thank you

If you have any questions please get in touch with me, Ketta Holder, Personal Social Services Research Unit, University of Kent, Cornwallis Building, Canterbury Kent CT2 7NF  
Telephone: 01227 827587 E-mail: [j.m.holder@kent.ac.uk](mailto:j.m.holder@kent.ac.uk)



## Parent's Consent Form

To be completed by Parent/Legal Guardian

(Legal parental responsibility means a child's mother, father if married to mother at time of birth or is named on the birth certificate of a child born after 01.12.05 or a person given such responsibility by Court Order)

This form is for you to give your permission for \_\_\_\_\_ to take part in a group discussion about what areas of life are important to children's wellbeing and what young people want from children's services. The Personal Social Services Research Unit, at the University of Kent is doing the research for the Department for Education. For more information please see the leaflet *Children and Young People: What do you want from services?*

Please complete in BLOCK CAPITALS

What is your full name?.....

What is the child's full name?.....

Do you have parental responsibility for this child? Yes  No

Does the local authority have parental responsibility for this child? Yes  No

Social Worker Name: ..... Tel No:.....

- I understand what the research will involve.
- I give my consent that he/she can take part in the group discussion.
- I know that he/she can leave the discussion if they want to.
- I am happy for the discussion to be recorded.
- I know the information will be kept private.

Signed.....

Date.....

When complete, please RETURN this form to \_\_\_\_\_.

Thank you. Ketta Holder, PSSRU, University of Kent, Tel: 01227 827587



## Group Discussion Topic Guide

Thank you for agreeing to take part in our study and for coming along today. My name is Ketta, and this is my colleague (insert name). We are researchers from the Personal Social Services Research Unit at the University of Kent. The research is funded by the Department for Education. The research project we're working on is exploring:

- **Quality of life** of children and young people
- **Impact** of services and support on their quality of their life.

We are holding a series of discussion groups with young people. The information will be used to develop a **questionnaire for young people to fill in about children's wellbeing and experience of children's social services**.

### Purpose of study

We want to listen and learn from you, as young people about

- Areas of your life that are important to your well-being
- Types of impact and improvement that support and services should aim to bring about

### Confidentiality and tape-recording

We really appreciate you sharing your views with us and would like to reassure you that

- Everything you say is **confidential**
- But if someone says they are at risk of harm, we'll tell someone who can help.
- You will remain **anonymous**. No-one will be able to trace back what you say to you.
- And with your permission we would **like to record** the discussion - so that we can analyse it in detail later and quote your words in reports. Recordings will be confidential.

### Ground-rules of focus groups

- Confidentiality - if you know each other, please keep what is said within this room
- Voluntary – you can leave the meeting at any time.
- You don't have to talk about something if you don't want to
- There are no right or wrong answers
- All views equally valid and valuable
- We want to listen to all your views and don't need you to agree with each other
- Different views are OK, everyone's different, and has different backgrounds and experiences...and understanding different viewpoints and opinions is important to us
- We'd like you to **share and compare** your views and opinions
- And we want to hear from everyone. Please be respectful, give each other the opportunity to talk and listen to each other's views. We'd like only one person speaking at a time please, everyone should have a chance to contribute.
- The session should last about 45 minutes.
- We're really interested in what you can tell us and we are here today to learn from you.
- **Any questions?**

### Introduction / warm up (5 minutes)

First of all we'd like to go round in turn and for you to tell us

- Your name
- *What's the best thing you've done over the summer and what are you looking forward to over the next month or so?*

**Group Discussion Topic Guide (continued)**

1. **What do young people value about their lives?** What is important to you and to your quality of life and well-being? What matters to you?
2. **What do young people want to be able to do?** (desired outcomes) e.g. be healthy... see friends)
3. **What do young people want to be able to feel?** (e.g. feel safe.. feel good about yourself)

**CIRCULATE LIST**

This is a list of what adult social service users have said they value and think is important. I'd like to go through it with you to find out if we've identified all the relevant and important areas:

- (1) If they are meaningful to you?
- (2) What they should be about? Try to develop a definition for each area....
- (3) If anything should be added? Let's talk about each in turn...

**What do young people value about their lives?**

- |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ol style="list-style-type: none"> <li>1) <b>Physical care</b> (enough healthy food and drink, warmth and shelter, clean suitable clothing)</li> <li>2) <b>Feeling safe and secure</b> (where you live and at school)</li> <li>3) <b>School</b> (can go, get help &amp; support you need to do best you can at school)</li> <li>4) <b>Help and encouragement</b> (to deal with problems and pressures)</li> <li>5) <b>Communicating</b> (able to have a say and info you need)</li> <li>6) <b>Feeling understood and being involved</b> (treated fairly, able to make choices, views taken into account)</li> <li>7) <b>Recreation and leisure</b> (do what want to do and do them enough)</li> <li>8) <b>Relationships with family</b> (enough contact with family who are imp to you/ quality of close relationships you would like)</li> <li>9) <b>Relationships with friends</b> (friends you feel are close/care about you, enough)</li> </ol> | <ul style="list-style-type: none"> <li>• <b>What does this mean to you?</b></li> <li>• <b>Is this relevant to young people?</b></li> <li>• <b>Is it important in your life</b></li> <li>• What would you call it? Does it make sense?</li> <br/> <li>• <b>What should it cover?</b></li> <li>• What would life be like if things were <b>going poorly</b> in this area?</li> <br/> <li>• What would life be like if things were <b>going well</b> in this area?</li> <br/> <li>• <b>What do you want your life to be like in this area</b> (now and in the future)?</li> <li>• What would you like to be able to do?</li> <li>• What would you like to be able to feel?</li> </ul> |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
4. **Is there anything missing from this list?** Is there anything that hasn't come up yet?
  5. **What do you need from services to help** achieve these positive outcomes?

(Children's services definition: include leaving care services, youth support services, family support services, young carers' groups, child protection and safeguarding services.)

**Thank you**  
**Circulate Characteristics Form and Vouchers**



## Group Discussion Self-Completion Questionnaire

1) Today's date: \_\_\_\_\_

Please tick [✓] one box

2) Are you:    a Boy        or a Girl   

3) How old are you? (Please write in) \_\_\_\_\_ years

4) What year group will you be going into at school this September? Year \_\_\_\_\_

5) Which of the following best describes you?

Please tick [✓] one box

- 1) White British
- 2) White Other
- 3) Black African
- 4) Black Caribbean
- 5) Black Other
- 6) Chinese
- 7) Indian
- 8) Pakistani
- 9) Bangladeshi
- 10) Other (please state)  \_\_\_\_\_

THANK YOU

## Appendix G Domains in existing social wellbeing, quality of life, health related quality of life and health status measures, surveys and indicators

Existing domains (Categorised as: ACTIVITIES, EDUCATION, ENVIRONMENT, HEALTH, PERSONAL, RELATIONSHIPS and SAFETY)		Sources
<b>ACTIVITIES/TIME USE</b> (linked to RELATIONSHIPS and ENVIRONMENT)		
1.	Activities – see also leisure activities, and social networks and social capital. Includes ‘time for’, how often, taking part in activities want. Sometimes asked about in terms of time use (see Time use below), or with focus on participation in physical activities only	ECM (make a positive contribution), KINDL_R, AUQUEI, Child QOL Questionnaire, Adolescent Wellbeing scale, Family Activity Scale (7 to 12 year olds), Young Lives Child Questionnaire (1 <sup>st</sup> round, 7.5-8.5 year old child). Family Activity Scale, State of the Nation’s Children, Ireland (2006), Child Health Utility Index 9D (CHU9D), British Household Panel Survey Youth Questionnaire (2009)
2.	Group membership (part of Societal participation domain)	OECD Family Database Child Outcomes – data is from World Values Surveys
3.	Play and imagination	CRISP Children’s Questionnaire, The Family Activity Scale
4.	Recreation and leisure (see also activities)	ECM (enjoy recreation, within Enjoy and Achieve). Strengths and Difficulties Questionnaire
5.	Time use	The Children’s Society index of children’s subjective wellbeing (How happy are you with the way you use your time?)
6.	Voluntary work, participation in (part of societal participation and social capital domain along with group membership)	OECD Family Database Child Outcomes, ECM (Make a positive contribution – engage in community)
<b>EDUCATION</b>		
7.	Achievement, learning, attainments, whether school work affected	CHIP-AE, ECM, Strengths and Difficulties Questionnaire, CHU9D, Generic Children’s QOL Measure Personal Wellbeing Index—School Children (PWI-SC)
8.	Employment	Common Assessment Framework (CAF)
9.	Enjoying and achieving	Every Child Matters
10.	School (see also achievement and attainment), school attendance, school satisfaction	ECM (attend and enjoy school and achieve stretching national standards), PedsQL, New Philanthropy Capital Well-being measure (in development), Dimension of child wellbeing with EU indicators, although not necessarily commonly agreed EU indicators –(see Poverty in EU report), German measure, Children longitudinal survey, CRISP Children’s Questionnaire, State of the Nation’s Children, Ireland (2006), HoNOSCA, The Children’s Society index of children’s subjective wellbeing, Personal Wellbeing Index—School Children (PWI-SC), British Household Panel Survey Youth Questionnaire (2009)
<b>ENVIRONMENT/EXTERNAL INFLUENCES</b>		
11.	Community – satisfaction with (see also Neighbourhood)	New Philanthropy Capital Well-being measure (in development), Personal Wellbeing Index—School Children (PWI-SC)
12.	Economic wellbeing (see also Material wellbeing)	Every Child Matters (Access to material goods and live in

<b>Existing domains (Categorised as: ACTIVITIES, EDUCATION, ENVIRONMENT, HEALTH, PERSONAL, RELATIONSHIPS and SAFETY)</b>		<b>Sources</b>
	below), money, possessions and standard of living	households free from low income within Achieve Economic Wellbeing) , Common Assessment Framework (Also asks about employment), The Children's Society index of children's subjective wellbeing
	Financial support / Income	KIDSCREEN-52, Personal Wellbeing Index—School Children (PWI-SC)
13.	Environment - Can include cultural and ideological environment	ECM (live in decent homes and sustainable communities), WHOQOL 100, Dimension of child wellbeing with EU indicators, although not necessarily commonly agreed EU indicators (see Poverty in EU report), State of the Nation's Children, Ireland 2006, The Family Activity Scale
14.	Environmental and family factors (see also staying safe and social)	Common Assessment Framework (CAF) includes quiet place for hobbies or homework and being free from harassment and discrimination
15.	Home	The Children's Society index of children's subjective wellbeing
16.	Housing	Dimension of child wellbeing with EU indicators, although not necessarily commonly agreed EU indicators –(see Poverty in EU report), Common Assessment Framework (CAF)
17.	Neighbourhood (see also social capital and overlap with safety), Local area (unspecified)	ECM (Access to transport within achieve economic wellbeing), The Children's Society Index of children's subjective wellbeing
18.	School environment (see also Bullying)	ECM (safe from anti-social behaviour at school) KIDSCREEN, Health Behaviour in School-Aged Children
<b>HEALTH</b>		
19.	Basic care (see also Family e.g. emotional warmth)	Common Assessment Framework, ECM (Being cared for is included within Staying Safe)
20.	Disorders	CHIP-AE (optional domain)
21.	Emotional wellbeing, including depression and anxiety, and mental health (See also Wellbeing and Happiness)	(Schalock 2004 identifies this as a core domain) Strengths and Difficulties Questionnaire , KIDSCREEN, TNO-AZL TACQOL, Child QOL Questionnaire, New Philanthropy Capital Wellbeing measure (in development), CRISP Children's Questionnaire, Adolescent Wellbeing Scale, EQ-5D-Y, HoNOSCA, CHU9D
22.	Health (also see Physical wellbeing)	The Foundation for Child Development Report (in Thomas, J 2009), ECM, The Children's Society Index of children's subjective wellbeing, Personal Wellbeing Index—School Children (PWI-SC), British Household Panel Survey Youth Questionnaire (2009)
23.	Hurt	CHU9D
24.	Medical/treatment – given medical help when you need it	CRISP Children's Questionnaire
25.	Pain and symptoms	TNO-AZL TACQOL; TAPQOL; Health Utilities Index Mark 2 and 3 , Child QOL Questionnaire, How Are You?, Exeter QOL Measure, CHU9D
26.	Physical wellbeing / Health status and functioning	HUI 3 ( 8 attributes with 5 or 6 levels ) Vision, hearing,

<b>Existing domains (Categorised as: ACTIVITIES, EDUCATION, ENVIRONMENT, HEALTH, PERSONAL, RELATIONSHIPS and SAFETY)</b>		<b>Sources</b>
		speech, ambulation, dexterity, emotion, cognition, pain) Health Utilities Index Mark 2 and 3 (sensation, mobility, emotion, cognition, self-care, pain, fertility), Australia's young people, their health and welfare 2003, KIDSCREEN, KINDL_R, PedsQL ; Quality of Life Questionnaire for Children; How Are You?, Child QOL Questionnaire, AUQUEI
27.	Self-care, self-care skills and orientation	Health Utilities Index Mark 2 and 3, Common Assessment Framework
28.	Sleep	Adolescent Wellbeing Scale for young people aged 11 to 16, CHU9D
<b>PERSONAL</b>		
29.	Appearance, body image and self-image	Child QOL Questionnaire, The Children's Society index of children's subjective wellbeing, Health Behaviour in School-Aged Children (HBSC), Integrated Children's System Exemplars, British Household Panel Survey Youth Questionnaire (2009)
30.	Autonomy / independence (see also having a say)	KIDSCREEN; TNO-AZL TACQOL, CRISP Children's Questionnaire, WHOQOL 100
31.	Behaviour	Strengths and Difficulties Questionnaire (SDQ), HoNOSCA
32.	Choice	The Children's Society Index of children's subjective wellbeing
33.	Civil life skills	Multinational Project for Measuring and Monitoring Children's Wellbeing
34.	Cognitive functioning	TNO-AZL TACQOL; How Are You?
35.	Comfort	CHIP-CE
36.	Daily routine	CHU9D
37.	Developmental needs	Common Assessment Framework
38.	Discomfort	CHIP-AE
39.	Food – satisfaction with	CRISP Children's Questionnaire, Adolescent Wellbeing scale, Young Lives Child Questionnaire (1 <sup>st</sup> round, 7.5-8.5 year old child), Adolescent Wellbeing Scale
40.	Future – looking forward to things, what may happen to you in later life	Adolescent Wellbeing Scale, The Children's Society Index of children's subjective wellbeing, Personal Wellbeing Index—School Children (PWI-SC)
41.	Happiness – self-reported (see also Wellbeing – general perceptions of)	How Are You? Tellus4, ECM (Engage in decision making is included within Making a positive contribution), State of the Nation's Children, Ireland, (2006)
42.	'Having a say', participation in decision-making, and/or ability to influence decisions (see also Rights framework)	Children's Rights framework, CRISP, State of the Nation's Children, Ireland (2006)
43.	Identity	Common Assessment Framework
44.	Life Satisfaction	HBSC
45.	Make a positive contribution (see also Activities)	Every Child Matters

<b>Existing domains (Categorised as: ACTIVITIES, EDUCATION, ENVIRONMENT, HEALTH, PERSONAL, RELATIONSHIPS and SAFETY)</b>		<b>Sources</b>
46.	Material wellbeing (see Financial and economic wellbeing)	(Identified by Schalock 2004: as a core domain), Multinational Project for Measuring and Monitoring Children's Wellbeing, Family Resources Survey, Dimension of child wellbeing with EU indicators – none of which seem to include self-report/childrens' views (see Poverty in EU report)
47.	Personal development	(Schalock 2004: core domain), ECM (self-confidence and achieve personal and social development) and Children's Plan 2020 Goals (positive activities to develop personal and social skills)
48.	Psychological wellbeing, moods and emotions	ECM, KIDSCREEN, KINDL_R, WHOQOL 100, Adolescent Wellbeing Scale
49.	Resilience	CHIP-CE, New Philanthropy Capital Wellbeing measure (in development)
50.	Satisfaction	Generic Children's QOL Measure, CHIP-AE
51.	Self-determination	(Schalock 2004: identifies this as a core domain)
52.	Self-esteem	New Philanthropy Capital Wellbeing measure (in development)
53.	Self-perceptions	KIDSCREEN
54.	Social Presentation	Common Assessment Framework (Focus –development and capacity rather than wellbeing per se)
55.	Stimulation	Common Assessment Framework (CAF)
56.	Time to be alone	Research with young carers, Holder et al., (2009), CRISP
57.	Wellbeing – general perceptions of	Young Lives Round One questionnaire, Australia's young people, their health and welfare 2003, Belgium – source Husbands, State of the nation's children, Ireland 2006, The Children's Society Index of children's subjective wellbeing, British Household Panel Survey Youth Questionnaire (2009)
<b>RELATIONSHIPS</b>		
58.	Attention and guidance	CRISP Children's Questionnaire
59.	Family – quality of relationships with (Overlaps with activities)	HoNOSCA, Child QOL Questionnaire, KIDSCREEN, AUQUEI, HBSC, State of the Nation's Children, Ireland (2006), Shanker et al. 2005 USA Health related quality of life of children undergoing therapy for cancer study, New Philanthropy Capital Wellbeing measure (in development), Dimension of child wellbeing with EU indicators, although not necessarily commonly agreed EU indicators –(see Poverty in EU report), Child Health Questionnaire CHQ, Australia (see Husbands), German longitudinal survey, family climate (See child poverty and wellbeing in EU report, European commission), CRISP Children's Questionnaire (people who love and care about you), Strengths and Difficulties Questionnaire (Home Life), Family Activity Scales, HoNOSCA, The Children's Society Index of children's subjective wellbeing, British Household Panel Survey Youth Questionnaire (2009)
	Family History and Functioning	Common Assessment Framework
	Family and Social Relationships	Common Assessment Framework

<b>Existing domains (Categorised as: ACTIVITIES, EDUCATION, ENVIRONMENT, HEALTH, PERSONAL, RELATIONSHIPS and SAFETY)</b>		<b>Sources</b>
	Birth family - relationships and contact with	Common Assessment Framework 'How happy are you with the love of your parents'
	Wider Family	Common Assessment Framework
	Permanence, placement stability	Common Assessment Framework
	Emotional warmth	Common Assessment Framework
60.	Guidance and boundaries	Common assessment framework
61.	Informed and skilled (e.g. given the information you need to make decisions)	CRISP Children's Questionnaire
62.	Interpersonal relations	SF-12 includes a 'social functioning' subscale(Schalock 2004: core domain), Tellus4, SDQ, HoNOSCA, Generic Children's Quality of Life Measure (GCQ)
63.	Just treatment – treated fairly by adults	CRISP Children's Questionnaire
64.	Opinions respected	CRISP Children's Questionnaire
65.	Peer relationships and friendships <ul style="list-style-type: none"> <li>- Opportunities to be with</li> <li>- Quality of relationships</li> <li>- Sometimes includes social support</li> <li>- Sometimes relationships per se (unspecified whether family or friends)</li> </ul>	Health Behaviour in School-Aged Children Study HBSC, State of the Nation's Children, Ireland (2006), New Philanthropy Capital Wellbeing measure (in development), Strengths and Difficulties Questionnaire, HoNOSCA, KIDSCREEN, The Children's Society Index of children's subjective wellbeing, Personal Wellbeing Index—School Children (PWI-SC), British Household Panel Survey Youth Questionnaire (2009)
66.	Respect (Could be part of Rights domain (see below))	Children's Rights framework, CRISP (do adults listen to and respect your ideas and opinions)
67.	Rights and respect	(Schalock 2004: core) See also Rights4Me.org, Young Lives Child Questionnaire (1 <sup>st</sup> round, 7.5-8.5 year old child), Children's Rights Framework
68.	Social inclusion (See also voluntary work, participation in and group membership))	(Schalock 2004: identified as core domain)
69.	Social capital/ support	Common Assessment Framework (CAF), Young Lives Child Questionnaire (1 <sup>st</sup> round, 7.5-8.5 year old child), Young Lives Child Questionnaire (1 <sup>st</sup> round, 7.5-8.5 year old child), AUQUEI, PedsQL; Quality of Life Questionnaire for Children, TNO-AZL TACQOL, How Are You?, KINDL_R, CRISP Children's Questionnaire, Dimension of child wellbeing with EU indicators, although not necessarily commonly agreed EU indicators –(see Poverty in EU report), Common Assessment Framework (CAF), Young Lives – 12 year olds
70.	Support	CRISP Children's Questionnaire, Young Lives – 12 year olds, CRISP Children's Questionnaire
71.	Teachers – relationships with	British Household Panel Survey Youth Questionnaire (2009)
<b>SAFETY</b>		
72.	Bullying – sometimes included within staying safe	KIDSCREEN, HBSC, State of the nation's children, Ireland

<b>Existing domains (Categorised as: ACTIVITIES, EDUCATION, ENVIRONMENT, HEALTH, PERSONAL, RELATIONSHIPS and SAFETY)</b>		<b>Sources</b>
	and school environment	2006, Tellus4, British Household Panel Survey Youth Questionnaire (2009)
73.	Risk avoidance	CHIP-CE
74.	Safety and security ( See also emotional safety)	ECM (Covers safety from crime and anti-social behaviour out of as well as in school. It also includes having security and stability and being cared for), Young Lives Child Questionnaire (1 <sup>st</sup> round, 7.5-8.5 year old child), Tellus4, State of the Nation's Children, Ireland 2006, CRISP Children's Questionnaire (people and situations), Dimension of child wellbeing with EU indicators, although not necessarily commonly agreed EU indicators –(see Poverty in EU report), Common assessment framework, Dimension of child wellbeing with EU indicators, although not necessarily commonly agreed EU indicators –(see Poverty in EU report), Scottish Crime Survey (SCS, 2003), Being Young in Scotland, Scottish Social Attitudes Survey (SSAS) – fear of crime, The Children's Society Index of children's subjective wellbeing, Personal Wellbeing Index—School Children (PWI-SC)