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CENTRE FOR CLINICAL AND
ACADEMIC WORKFORCE INNOVATION

UNIVERSITY OF
LINCOLN

Improving Identification and Audit of Disability within Child Health Services

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Executive Summary

Introduction – The Purpose of the Audit

In order to support achievement of the Aiming High for Disabled Children: Better Support for Families 'core offer' and achievement of PSA target 12, indicator 5 it is important that disabled young people and their families can report a more favourable experience of community services. The Centre for Clinical and Academic Workforce Innovation (CCAWI) was commissioned to undertake a survey of existing data collections across health, education and social care in order to evaluate their usefulness in audit of childhood disability and to collect definitions of disability from across the three domains.

The purpose of this project was to survey existing data collection methodologies across health, education and social care in order to evaluate their usefulness in audit of childhood disability and collect definitions of disability from across the three domains. This should inform commissioners, providers and practitioners across organisations that work with children in the collection of useful data around children's disability, and in the design, development and provision of appropriate, accessible and responsive services for children.

Key Findings

- The survey located a large number of datasets that contain information regarding childhood disability. Differences in the definitions of disability and criteria used to define children's eligibility in relation to disability make comparison of existing figures difficult and limit the ability to bring together documents for the purposes of audit.
- Everyday data collections across health, education and social care lack consistency both between local authorities and within agencies in the same local authority.
- Categories of disability are relatively unstable across health, education and social care, therefore making it difficult to establish a comprehensive and useful audit that assimilates current data collections around childhood disability.

- A consistent approach to data collection can relieve the difficulties established within this audit.
- The development of an integrated data tool the may facilitate future data collections across all three domains. The International Classification of Functioning Disability and Health –Children and Youth version (ICF-CY, World Health Organisation, 2007), had been identified as a possible solution to this. Implementing a unified approach will remove the disparities found in current data collections.
- Until such time as a unified approach to data collections is established it is necessary to take a developmental 'stepped change' approach to considering the problems associated with the current method of data collection. It may be possible to match the areas in which existing data collections overlap. This would provide the first stage to considering some of the difficulties highlighted by this audit, until such time as the utility of an integrated framework can be tested across children's services. This would require children's services to come together to map their data collections and identify areas of overlap and potential gaps.
- It is essential that some way of tracking individual children with disabilities through the services is established, this will reconcile the problems of double counting.

Background

In recent years significant policy changes have sought to improve the health and wellbeing of children and young people particularly those who have disabilities or complex needs. The publication of the Aiming High for Disabled Children: Better Support for Families has made disability an urgent government priority. In order to support this priority the government have set a performance target (PSA 12; indicator 5) to support delivery of the 'core offer' which states that disabled children and their families should be able to report a more favourable experience of local services. In order to ensure that these experiences are more favourable it is necessary that disabled children and their parents receive clear information regarding their entitlement to services and that services are delivered responsively to areas of need. In order to supply services to areas of need it is essential that data collections across health, education and social care are able to be used effectively to inform on planning and commissioning and that the eligibility criteria for receipt of these services is transparent.

Aims of the study

The broad aims of the study were:

- To identify definitions of disability

- To review existing data collections methodologies across health, education and social care that might provide auditable information on disability

More specifically the project aimed to:

- Examine the literature on childhood disability and identify where there was common agreement on definitions between and within conditions and models of care

- Compile a list of definitions that are specific enough to direct service delivery whilst being broad enough not to exclude children with needs
- Agree definitions with ‘expert reference group’ (see appendix A)
- Critically review the most commonly used data collection methodologies in England and identify areas of agreement between the different methodologies and the definitions agreed with the ‘expert reference group’.
- Make recommendations on the best use of the current data collection methodologies and how best to move to implementing a more coherent and consistent methodology that would better inform service providers and commissioners

Methodology

The study was conducted over three phases:

1. Evaluation of existing data sets containing auditable data on children’s disability, the collection of definitions of disability and the mapping of definitions to an integrated matrix
2. Emails consultation with an expert working group for evaluation of the format and content of the documents.
3. Consultation with the expert working group in order to evaluate the final draft definitions emerging from the project and recommendations for taking forward the outcomes of the project.

The initial collection of existing data sets and definitions of disability was achieved through a systematic review of health, education and social care databases and a search of open internet resources. The results of phase 1 were compiled and sent electronically to the twelve consultants on the expert working group, responses to the documents were received electronically and used to re-evaluate the project findings. The final phase consultation meeting with the expert working group of six professionals evaluated the results of the project and suggested recommendations for implementation of the results of the project.

Findings

Survey of existing data collections

Current data collections vary both between and within local authorities. The type of data that each domain (e.g. health, education and social care) will use and the way that they define their categories of data collection is heavily reliant upon the model of disability to which the service subscribes. This leads to variation between the domains as to what data they will collect, for example in health data is often related to medical diagnosis rather than to participation issues (functional levels that the child exhibits). The study revealed a number of national surveys that collect data on an annual or ten year basis and a number of individual research projects that had investigated the usefulness of national data sets. Within these studies there is a lack consensus as to what should be collected. The results to all of the individual research projects evaluating the usefulness of such data sets concluded that due to inconsistencies in the definitions and criteria for measuring disability current data sets were not comparable. However, these studies can be used to facilitate a ‘rough’ estimate of the prevalence of childhood disability. At least one data set that will be release in the near future will attempt to clarify some of the current issues with data collections (Children in Need Survey, 2008/09). The lack of consensus raises serious problems for audits of figures that explore childhood disability.

Definitions of disability

As previously suggested the definition of disability positively affects the data collections and the prevalence figures that will be generated from such studies. Investigation of the definitions revealed that it is possible to define disability in children on three levels:

- Generalised definitions provide encompassing criteria that attempts to act as an umbrella which describes the nature of what it means to have a disability. These are vulnerable to being over inclusive for the purposes of audit as they will encapsulate every child who has a long term illness.
- Categorical definitions provide definitions of childhood disability that are broadly linked by the function that they affect. It is this level of definition that is considered to be the most useful in audits of childhood disability figures and these categories can be predictive regarding the type of services that a child may need. However, the categories of disability that are defined vary across studies and across the domains of health, education and social care.
- Individual condition definitions capture very specific areas of childhood disability. These definitions are highly prescribed and are useful for addressing the needs of a very specific group of children.

Following consultation colleagues agreed that one way to resolve issues regarding current data collections was the development to an ‘integrated’ coding system that could be utilised by the domains of health, education and social care. In a gap analysis it was possible to match individual conditions definitions and categorical definitions to a matrix based on the International Classification of Functioning, Disability and Health – Child and Youth Version, (2007). The gap analysis revealed areas where a consensus of agreement between domains was possible and also gaps that would need to be addressed should the integrated coding system be adopted. The placement of the definitions in the matrix was agreed by a consultation group and it was proposed that further information be sought from a research group in Europe (Measuring Health and Disability in Europe Consortium) who had made policy recommendation for the adoption of this integrated tool to the European Parliament in Brussels (16th September, 2008).

Discussion

Existing data sets that contain auditable data on childhood disability have a limited capacity to be used in the planning and commissioning of services. Figures that are available can be used to give an estimate of prevalence figures at both the local and national levels. However, these figures should be used with caution all current collections have both strengths and weakness which need to be taken into account prior to use.

All local authorities have some form of data collection unfortunately these are all at different stages of development at this time. In order to begin to resolve the data issues it is important that professionals now begin to consider their data collections in a different way and begin to think strategically about the usefulness of such data sets in the future, particularly if these are to be used for the purpose of planning and commissioning services that are requires in local areas. The scoping work undertaken during this study suggests that the development of an integrated coding system that can be used both between and within authorities on a national level can relieve the current difficulties with conducting audits on data sets which explore childhood disability. Until such time as the development of such an integrated coding system is possible it is recommended that professionals begin to look at the data they hold and match where possible categories of disability that accommodate some consensus of agreement with regard to definition and eligibility criteria across the domains of health, education and social care as demonstrated in our gap analysis. In essence it is suggested that where previously authorities would have explored each data set individually they should now begin to map across these.

Recommendations

1. In order to overcome the potential vulnerabilities of current data set and to develop a comprehensive approach to data collection, it is recommended that a developmental ‘stepped change’ approach is taken to resolving data collection issues. This development work should extend across the domains of education, health and social care. It is recognised that an immediate whole system change is inappropriate, given the extent of the issues raised by this project. Therefore successful adoption of a new system of integrated data collection would incorporate the following stages:

    a. To enable the initial stage of the process, it is recommended that commissioners, providers and professionals from across children’s services should collaborate to map current databases in use and agree areas of consensus. This could be done on a local or regional basis.
    b. There is also a need to identify possible areas where double-counting could occur, and to put structures in place to assist in reducing the occurrence of this. For example, a tracking or individual case identification system.
    c. It is vital for commissioners, providers and professionals working in children’s services to consider the variability and reliability related to current data collections of childhood disability and begin work to establish consistency in the way that data is collected and coded data.

2. An integrated framework should be developed and agreed across the domains of education, health and social care at a National level. This would steer the successful implementation of the ‘stepped change’ approach suggested. The ICF-CY should be considered as an option for providing this framework due to its international agreement, its research base and its previous success in harmonising data collections in Europe.

3. Pilot studies investigating the utility of the ICF-CY should be undertaken across five local authorities (these should include one in the London area) in England. This will enable professionals in education, health and social care to establish what this coding system means for them and assess the impact that this framework has on harmonising the data sets across domains.

4. In order to overcome the issues of double counting a method of identifying children should be established. There are current plans to develop unique identifier numbers for children, however, one alternative may be to collect birth certificate numbers.

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Improving Identification and Audit of Disability within Child Health Services

1. Introduction

This project was commissioned by the Care Services Improvement Partnership (CSIP) through their National Children's Improvement Services, and is funded by the Department of Health. The National Children's Improvement Services form the national component of CSIP's Children and Families Programme. Their remit is to support local attainment of the standards set out in the Government's "National Services Framework for Children, Young People and Maternity Services" (2004) which is the "Be Healthy" element of the Every Child Matters programme (2007). One of the objectives is to develop a Child Health and Maternal Health Intelligence Unit (ChiMat). ChiMat will work with health information providers to offer access to information and knowledge through which the planning and delivery of high quality, cost effective services can be facilitated.

The purpose of this project was to survey existing data collection methodologies across health, education and social care in order to evaluate their usefulness in audit of childhood disability and collect definitions of disability from across the three domains. This should inform commissioners, providers and practitioners across organisations that work with children in the collection of useful data around children's disability, and in the design, development and provision of appropriate, accessible and responsive services for children.

2. Background

In recent years there have been significant changes in policy that have sought to improve the health and wellbeing of children and young people particularly those who have disabilities or complex needs. In 2004, the National Service Framework for Children and Young People and Maternity Services (NSF) sets out eleven standards for best practice. Standard eight addressed the needs of disabled children. Standard eight suggests that in order to achieve the standards within the NSF for children and young people who are disabled or who have complex health needs, they must "receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives" (DH, 2004).

One key factor in attaining the standards set out by the Department of Health is the need for integrated cooperative working between professionals in health, education and social care. The Every Child Matters: Change for Children programme (DfES, 2007) has suggested new ways of working which integrates services, discusses effective information sharing and works towards facilitating clearer information for parents and young people particularly when they are service users. The introduction of Aiming High for Disabled Children: Better Support for Families (Department for Education and Skills, 2007) has made disability an urgent government priority. It sets out a 'core offer' or statement about what entitlements and services disabled children, young people and their families can expect. The ‘core offer’ to disabled children and their families encompasses standards for five areas;

- clear information
- transparent eligibility criteria and process for accessing services
- multi-agency assessment
- participation in shaping local services
- accessible feedback/complaint mechanisms

(Department for Education and Skills, 2007).

These five areas play an essential role in providing good services and ensuring that all eligible children are able to access the services that are essential to supporting their development and needs. It is also important that the parents of children who have disabilities have a positive experience of services if they are to feel supported by children’s services and organisations across health and local authorities. In order to support the government’s priority on disability, delivery of the ‘core offer’, which is the governments commitment to improving services for disabled children and their families, was included in the public service agreements (PSA) for the period 2008 to 2011 (HM Treasury, 2008). Delivery of PSA target 12 is the responsibility of both health and local authority services. They will be required to commission and deliver community health services for the care management of long term conditions including disability. Indicator 5 of the PSA target 12 states that disabled young people and their families should be able to report a more favourable experience of these services once the ‘core offer’ has been implemented.

The comprehensive commissioning and consistent and sustained delivery of good quality services for children with a disability depends, in large part, on the ability of service providers to understand the prevalence and incidence of disability (in children) in any particular area or region. If this information is to be meaningful there is a need for nationally agreed definitions of disability and data collection. This would facilitate the development of services based on evidence based or best practice that were centred on the needs of those who use services, regardless of where they live.

Developing responsive services and working in the area of disability is particularly challenging due to disparities between the definitions of disability that are adopted. These definitions vary both between and within organisations and are highly dependent upon the model of disability to which the organisation subscribes. This has led to the use of different languages to describe the same conditions and, conversely, the use of the same words with ascribed different meanings; this lack of a common language has contributed to a lack of consistency in both data collection and service delivery.

In order to enable integrated working between the domains of health, education and social care it is vital that definitions can be agreed that are relevant and useful to all parties concerned. The adoption of integrated definitions will enable clear criteria for eligibility to be established and will facilitate the achievement of the standards from the ‘core offer’ (DfES, 2007). The development of integrated definitions also can be used to ensure that data collected by different agencies can be brought together and shared in order to facilitate the collection of auditable information on disability. Such information can then be used in the planning and commissioning of services both on a national level and in regional and local areas. Planning using actual population data can help to ensure that services are provided in the areas in which they are required and contrastingly services that are unnecessary or less helpful to the regional population can be identified. In addition a shared understanding of disability would be helpful in terms of improving communication between the array of professions that are typically involved in children's care.

3. Methodology

The broad aims of the study were:

- To identify definitions of disability
- To review existing data collections methodologies across health, education and social care that might provide auditable information on disability

More specifically the project aimed to:

- Examine the literature on childhood disability and identify where there was common agreement on definitions between and within conditions and models of care
- Compile a list of definitions that are specific enough to direct service delivery whilst being broad enough not to exclude children with needs
- Agree definitions with 'expert reference group' (see appendix…..)
- Critically review the most commonly used data collection methodologies in England and identify areas of agreement between the different methodologies and the definitions agreed with the 'expert reference group'.
- Make recommendations on the best use of the current data collection methodologies and how best to move to implementing a more coherent and consistent methodology that would better inform service providers and commissioners

The work was conducted over three phases which consisted of:

1. An **audit of available data** on Children's Disability and the development of a draft integrated definition of disability.
2. **Consultation with the expert working group by email** during August on the draft definitions of disability developed at this stage of the project and a re-evaluation of the format and content of the documents. This consultation exercise also required the group to raise issues and questions that needed to be considered by the project team, in order to take the pieces of work forward and to ensure that the outcomes were responsive.
3. An evaluation of the final draft definitions emerging from the project and agreement on the final versions. Recommendations were made for taking implementation of the outcomes of the project. This phase required Expert Working Group members to attend a **consultation exercise on Tuesday 9th September, 2008.**

Phase 1

The study employed a systematic review of academic databases between the years 1989 and 2008. A number of search terms were developed and applied to the databases (see appendix A for details). The abstracts for returned articles from the databases were sorted by relevance and the first 500 items from each search were surveyed. Full versions of documents which contained or appeared to contain auditable information or definitions of disability were obtained.

In order to survey existing data collections for auditable information on disability the following search terms were used:

disability **child*** **prevalence**

To identify possible definitions of disability the following search terms were used in the databases:

disability **child*** **definitions**

categories **descriptors** **classifications**

indicators

Below is a list of databases selected for review, these are known to contain information that covers all three areas of interest.

Academic search Elite
ASSIA
Bio-Med Central
Economic and Social Data
Child Data
International Bibliography of Social Sciences
PsycINFO
Science Direct
Social Science Citation Index
Lincolnshire Research Observatory

CINAHL
Australian Education Index
Cochrane Library
British Education Index
ERIC
MEDLINE
Science Citation Index
Social Care Online
Index to THESIS
intute

A brief survey of open internet resources using the same search terms as the systematic review was also conducted to capture any ‘grey’ literature not referenced in published academic journals. The first five pages of items returned from open internet resources (e.g. Google) were surveyed and relevant documents were either coded or downloaded where available.

Previous surveys and data sources that may be used to ascertain the prevalence of childhood disability were accessed and their usefulness was evaluated.

Definitions of disability spanning three levels; generalised, categorical and individual condition, were collected.

Phase 2

A total of twenty-nine colleagues were invited to take part in e-mail consultation. Seven declined, eight did not respond to e-mail invitations and two e-mails were returned due to incorrect addresses. Twelve colleagues agreed to take part in the e-mail consultation phase, of these seven responded via e-mail to the consultation document.

A copy of the consultation document dated 6th August 2008 which included the following questions was sent to the group.

1. We ask the group to agree on the coding system that should be used across the three domains (Health, Education and Social Care); we believe that once this decision is made and implemented it will be possible to provide auditable information that can be used in the commissioning and planning of services.
2. Do the group agree that one model (e.g. the International Classification of Functioning, Disability and Health-Child and Youth Version (2007) can be used as a shared 'integrated' model for coding details of childhood disability?
3. Can the group decide which level of definitions should be used in order to collect data? Should it be generalised, categorical or individual?
4. Do they agree on where we have placed the definitions in the matrix? If not can they make suggestions for where items should be placed?
5. Do the group feel that any relevant information has been missed from the review or that any of the findings so far are inaccurate? If so, can they suggest what should be added? Or why the findings to data are inaccurate?
6. How would the group establish the boundaries of eligibility criteria within the matrix?

The resulting comments from the consultation group were collated and used to inform the project team on amendments to the consultation document and to gaps in the research to date.

Phase 3

A total of 29 colleagues were invited to attend a consultation exercise on the 9th September 2008 during which the results of phase 1 & 2 of the project were presented and colleagues were invited to comment on the findings and the consultation document. A total of eleven colleagues attended the consultation meeting; six of the delegates were professionals who work in areas related to children's services, one delegate was the commissioner for the work and the other four were members of the research team. Following a presentation of the work undertaken in the project delegates discussed a number of issues arising from the findings. Colleagues were also asked to make recommendations for implementation of the outcomes of the project.

The group were asked to address the following questions:

1. Can the group make suggestions for filling the gaps in the themes?
2. Do the group agree with the themes drawn from the definitions of disability? If not, how would colleagues change these?
3. How can these themes be used to establish eligibility criteria?
4. Do the group have any suggestions for a strategy that can be used to implement the outcomes of this project?

4. Findings

4.1 Survey of Existing Data Collections

The agencies within the domains of education, health and social care all currently maintain some form of data collection. In education data regarding eligibility for educational assistance is recorded on a regular basis and is reported each year in an annual review. Health care agencies collect data regarding diagnosis of medical conditions on a day to day basis; these systems and the exact nature of the data collected can vary both within and between health care regions but often this will take the form of International Classification of Disease classifications or Read codes. Read codes are a coded thesaurus of clinical terms which enable clinicians to make effective use of computer systems

In social care, assessments of need are frequently made in order to provide services to individuals. Decisions regarding the format that such data collections will take are often reached at a local level and this has lead to an inconsistent approach to the way that disability is defined and measured.

A number of national surveys that operate periodically also collect data on childhood disability; existing surveys that have investigated the usefulness of national data on disability were located during the systematic review. The results of these studies were checked for accuracy and agreement was reached between the current project and those previously published. The previous surveys are discussed in detail here, followed by an evaluation of those data sets not included or updated since their use in the previous reviews.

Hutchison and Harpin (1998). Survey of UK computerised special needs registers.

Hutchison and Harpin (1998) conducted a postal survey of special needs registers in the UK. The study received a high return rate of 93%. The results suggested that while a high proportion of districts had special needs registers (56%) very few of these were able to use the system to identify the type of disability of those registered, the needs of children with disabilities or to use this data for planning of services. In their conclusions Hutchison and Harpin (1998) propose that:

> *"…there should be continued cooperative work towards a national consensus on the categories of disability and definitions of severity of disability used in these registers" (page 315)*

These results were not confined to this study alone. A second similar study was conducted by Johnson and King (1999). Johnson and King (1999) investigated eight child health systems in three counties in England and compared the data held on these to a population register of children with disabilities. The experimental aim was to establish whether it was possible to determine prevalence rates of children with disabling conditions using the child health systems within local authorities. Key findings of the study demonstrated that when using information from the child health systems there were two types of mismatch, false positive (where a child had a diagnosis which suggested a disabling health condition was present but were not included on the population register) and false negatives (where children had no diagnostic code but were included on the population register). The authors concluded that while potentially the child health registers should be able to provide information on childhood disability and be available to be included in audit, inconsistencies between coding systems prevents this from being the case (Johnson and King, 1999).

North East Public Health Observatory: Children with Long Term Disability in the former Northern & Yorkshire NHS Region (Parker et al, 2003):

In 2003 the North East Public Health Observatory investigated child health and local authority registers of disabled children and prevalence estimates for childhood disability based on literature. The review found that there was a lack of consensus between local authority's approaches to what should be included in the registers of children with disabilities and that many authorities had not developed these with a view to inform on service planning. The review also suggests that while some data may be used to estimate the prevalence of disability (OPSC survey) there was a lack of national data for disabilities such as hearing and vision impairment, severe injury, mental health and autism. The review did suggest that data collected in respect of congenital anomalies, cystic fibrosis, diabetes and cerebral palsy could be used to estimate the prevalence of those specific conditions (NEPHO, 2003). The review concluded that collecting data regarding disability was inherently difficult while there was no consistent agreement on the definitions and that in order to maximise the usefulness of children act registers for children with disabilities, co-ordination of data is required that will ensure the quality and usefulness in the future (NEPHO, 2003).

Hutchison and Gordon (2005) conducted a study to ascertain the prevalence of childhood disability by comparing the results of the Office of Population Census Survey (OPCS) of disability (1985) to prevalence data based on the carer's views and medical records. This study suggested that the OPCS criteria yielded higher prevalence of disability than those collected from parents and medical records. Hutchison and Gordon (2005) suggest that this disparity is caused by the difference in the threshold criteria used in the OPCS survey. This study supports the view that when applying different definitions of disability to data the outcome of prevalence is directly influenced.

Can We Count Them: Disabled children and their households (Read, 2007):

Read (2007) conducted a review of all national data sets from the year 2000 onwards and provides a quality assessment of twenty-nine different surveys that hold data regarding disabled children. The data sets investigated by the Read (2007) study all produce data at regular intervals, often on an annual basis. The surveys vary in the depth of information that they collect on childhood disability, some request only a single yes / no response to the presence of a disability while others request diagnostic information using ICD codes or classifications developed by the authors. The following data sets were included in Read's study:

The Family Resources Survey a cross-sectional study which is conducted by the Department for Work and Pensions on an annual basis. The results from the survey are used in customer service planning.

The Population Census a cross-sectional study which is conducted by the Office for National Statistics every 10 years.

The General Household Survey a cross-sectional study which is conducted by a number of organisations on an annual basis.

The Family Fund Trust a continuous form of data collection which provides extensive data on severely disabled children.

Read (2007) produced results that suggest that although data sources may be able to identify children with long-standing illness and disability the current data collection can not discriminate between those who have mild conditions and those that have severe disabilities. In the conclusions to the report Read (2007) highlights a number of important findings which suggest that current methods of collecting data on disability are inadequate. Read (2007) states that prevalence rates *"vary from 5% to 18% depending on the definition/measure used"* and that *"different sub-classifications limit comparison between surveys".* These conclusions support the need for a consistent, nationally recognised coding system that can be used across domains to enable future collection of prevalence data. The coding system adopted must also be flexible enough to permit severity measure for disability. A coordinated approach will relieve the inconsistency between current data collections.

Disabled Children: Numbers, Characteristics and Local Service Provision (Mooney, Owen and Statham, 2008):

A final study that reflects the difficulties and disparities between the data that is currently available for assessing the prevalence of childhood disability is that of Mooney, Owen and Statham (2008). Mooney et al (2008) conducted a survey of local authorities with the aim of examining the prevalence of disabled children within local areas. Mooney et al (2008) received a 77% response rate to their questionnaire study. Results of the study suggested that while most local authorities (97%) could provide prevalence figures for the number of disabled children in their area there was variation in the way that these were calculated. Some local authorities provided actual counts from data held, while others provided estimates based on national prevalence figures. Results of the study also revealed that the definitions of disability used to calculate prevalence figures varied between authorities and sometimes within authorities. The definitions of disability adopted depended on the model of disability the authority subscribes to and by the thresholds that were used in order to calculate eligibility.

"*The authority as a whole subscribes to a social model criteria and definition of disability, although individual service providers will operate their own threshold and eligibility criterion".* (Page 30)

Another important finding of the study was that of possible double counting of children. In the authorities where more than one source was used to supply a prevalence measure not all respondents could adequately ensure that children were only included in the figure once. This vulnerability to double counting may lead to serious overestimation of prevalence rates within local areas, especially when many children with disabilities have co-morbid conditions (i.e. having two or more conditions simultaneously). With all these considerations in mind Mooney et al (2008) concluded that:

"Given the significant variation in definitions and criteria it is not possible to estimate the number of disabled children for each local authority based on the information provided in our survey." (Page 44)

Another key finding was that Child Disability Registers were not considered to be fit for use for audit purposes. Firstly, because registration is voluntary, the data collected does not reflect accurate figures for childhood disability prevalence. Secondly, because many authorities lack resources to maintain their data regularly, there are high levels of variance between the uses of registers within and between local authorities.

Mooney et al (2008) do propose that prevalence figures for disability can be estimated to be between 3.0 and 5.4 percent of children under the age of 18 years and that this estimate is taken from a number data source including SEN statements, the 2001 census figures, the Children in Need (2005) survey, the Family Resource Survey (Department for Work and Pensions) and OPCS. All of these data sources, except for the census data, produce annual figures that include the number of children with disability.

Clear conclusions can be drawn across all of the studies identified by the systematic review;

- It seems that due to differences in data collection, differences in coding and storing data and differences in the definitions and thresholds used to classify children as having a disability, audits of prevalence based on current surveys at this time can only provide a rough estimate.
- Some data exists that can describe and quantify prevalence for certain disability groups in specific geographical areas, these sources include the Cerebral Palsy Database which is maintained by the University of Liverpool. The University of Liverpool has continually developed their procedures in order to overcome the difficulties associated with confidentiality and

- Both of the above issues limit the usefulness of such data in the planning and commissioning services at both a local, regional and national level but do provide some estimated measures which may be of use depending on the purpose.

Possible solutions to the issues highlighted above have been considered in EIRE. In order to overcome the problems that are associated with current data sources, a recent National Disability Survey (National Disability Authority, 2006) has been conducted. The survey contains a questionnaire aimed specifically at children and asks detailed questions regarding children's disability. The survey takes nine categories of disability (Seeing, Hearing, Speech, Mobility and Dexterity, Remembering and Concentrating, Intellectual and Learning, Emotional, Psychological and Mental Health, Pain and Breathing) and then explores these in greater depth, e.g. if an individual had an impairment of vision the interviewers would ask what visual aids were used or what disease or illness was the main cause of the difficulty. This survey allowed in depth information about children's disability to be explored. One possible option to overcome the difficulties with data collections in England may be to replicate this disability survey so that accurate figures can be obtained.

In addition, the following recent sources of data were obtained, which have not previously been included in the surveys so far. These sources may be able to offer useful data on childhood disability.

Family Resource Survey 2006/07:

This annual survey contains data which includes coding for disability, long-standing illness and infirmity, all respondents coded as disabled are covered by the Disability Discrimination Act (1995) definition. The survey also contains information on the number of people receiving income related disability benefits such as Carer's Allowance and Disability Living Allowance. The results include rates of disability across a number of age ranges, the age group most relevant for the current project are those within the 0-15, results are also aggregated by gender. The survey suggests a prevalence rate of 5% of individuals in this age range have a disability, this figure includes children and young people with limiting long-standing illnesses (Department for Work and Pensions, 2008). However, this figure is only a rough estimate of disability prevalence across England, this survey does not include individuals who are in the high socio-economic bracket, and there are problems in applying the Disability Living Allowance criteria to all children with disabilities as only those with severe conditions are accounted for. There are also some problems with capturing data from minority ethnic groups and the figures presented do not accommodate the interests of the educational domain.

Special Educational Needs in England (2008):

This data base provides annual figures for children with Special Educational Needs in schools across England. However, the figures provided only cover pupils who currently have a statement of special educational needs and do not account for other types of disability where the child may not receive such a statement. The data presented in this set successfully captures children who have special educational needs but may neglect to account for children with disabilities who do not need services in this area. These problems limit the usefulness of this data to the planning of educational needs rather than across all three domains.

Children in Need Survey (2008/9):

Although the results to the 2008/9 survey are not yet available it is anticipated that the figures contained in this survey will be able to give detailed information on childhood disability. The survey will include definitions of disability and will return details for every child who receives a service.

Summary of findings: Survey of existing data collections

- **Current data sets have serious limitations which affect their usefulness in audit**
- **Classifications and definitions used in data collections influence the prevalence figures making them unstable across surveys**
- **It is difficult to match categories across the domains of education, health and social care due to differing definitions**
- **Local authorities vary in their approaches to data collection**
- **Current figures can only offer an estimate of childhood disability**
- **Child Health Systems, diagnostic information from health, SEN data collections, assessments of need and information collected by local authorities on a day to day basis all have the potential to provide auditable data, provided a consistent approach is agreed**
- **Local authority registers of disabled children are not able to inform on prevalence figures**
- **National surveys such as SEN data, census figures, the Family Resources Survey and Children in Need survey can be used to provide estimates of disability**
- **Problems of double counting must be addressed**

4.2 Survey of definitions of disability

Results demonstrate that the definitions of disability vary according to the model of disability applied. There are two core models of disability, the medical model and the social model.

- The *medical model of disability* is focused on the individual and looks at those who have disabilities in terms of deviance from the norm or sufferers of medical conditions or trauma (Bickenbach, Chatterji, Bradley and Ustun, 1999). The core concept of the medical model is the diagnosis of a medical condition(s) which is either the result or the catalyst of disability.
- Contrastingly, *the social model of disability* is central to social care and perceives disablement as a reaction to oppression in a society which only caters for the mainstream of the population and neglects to anticipate the needs of those who do not fit into this category. According to this model, impairment of function is a less frequent but normal occurrence and should be expected and accounted for if the population reflects a normal distribution (Bickenbach et al, 1999, Oliver, 1996 and 1990; Abberley, 1987). When adopting this model individuals have impairments of function but are disabled by their environment.

The key difference between the two models is that from the medical model the individual is disabled because they are different to mainstream society, whereas the social model suggests that it is mainstream society that disables people by failing to account for those with impairments. This polarisation is unhelpful, both models have strengths and a more integrated model would help services to work together to meet the needs of those who use them.

Results also reveal that it is possible to discuss and define disability on three levels-

- general encompassing definitions,
- categorical definitions
- individual condition definitions

All three levels are discussed in detail below.

Generalised Definitions

The systematic review uncovered a large number of different definitions of disability, a selection of which are presented here. Generalised definitions of disability provide inclusive descriptions that can be applied to all individuals who have long-standing conditions or illnesses (those that last at least 12 months) which disadvantage the individual from participating in normal activity. Three definitions applied exclusively to children, however, it is suggested that when using the other definitions in relation to children, deviations from typical child development should be applied as a measure for assessing disability. The review also uncovered a historical shift in the manner in which disability was discussed and defined. The historical shift relates to the development of different models of disability particularly the adoption of the social model of disability that is widely used by social care workers.

The earliest definition of disability addressed by this study was that produced by The World Health Organisation (WHO) in conjunction with their development of a coding tool that could be used with individuals who had long-standing illnesses or disabilities. The WHO's original definition had three components:

*"**Impairment**: any loss or abnormality of psychological, physiological or anatomical structure or function.*
***Disability**: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.*
***Handicap**: a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual."*
(World Health Organisation, 1980)

However, this definition was considered oppressive to disabled people and the Union of Physically Impaired Against Segregation (UPIAS) proposed a new definition of disability which laid the foundations for the social model of disability. The proposal received support from Disabled People's International (DPI) (Siminski, 2003) and together UPIAS and DPI produced their own definition of disability as an alternative to that offered by the World Health Organisation. This definition suggests that disability is not something that exists within the individual but is a product of society.

*"**Impairment**: is the functional limitation within the individual caused by physical, mental or sensory impairment.*
***Disability**: is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with other due to physical and social barriers."*
(DPI, 1982)

Whilst the two previous definitions are revealing regarding the evolution of different models of disability they have been superseded in their usefulness by more recent legal definitions in Britain. The first of these definitions comes from the Children Act (1989) which defines a disabled child as:

"Blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed; and in this part – 'development' means physical, intellectual, emotional, social or behavioural development; and 'health' means physical or mental health." Section 17 (11)

However, the utility of the definition as set out in the children act is debateable. In consultation with colleagues throughout this project, many professionals objected to the language used. In America a similar definition has been produced which aims to enable disabled children and their families to access services. Their definition states:

“Child with a disability”
In general – The term “child with a disability” means a child with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (hereinafter referred to as “emotional disturbance”), orthopaedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities;” (IDEA Definition of Disability, USA)

During the last fifteen years many European countries have developed disability discrimination law or acts to protect individuals with disabilities from being disadvantaged in education, health and work environments. The Disability Discrimination Act was formulated in Britain in 1995 and provides a legal definition of disability which says:

“Subject to the provisions of the schedule 1, a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.” (Disability Discrimination Act, 1995)

This is then mediated by a set of criteria which are used to quantify the eligibility of the individual to fall under the definition. These criteria include details of the types of disability covered (e.g. physical, mental health, learning and sensory impairment), classification of normal day to day activities (e.g. mobility and sensory attributes) and exclusion criteria (e.g. a classification of disfigurement is not made if the problem is caused by tattoos and body piercings). This legislation was followed in 2005 when the Republic of Ireland also produced a disability act which contained the following definition.

“…”disability”, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment;” (Disability Act, Eire, 2005)

The movement of disability acts throughout Europe was followed by the UN’s Convention on the Rights of Persons with Disabilities (2006) which sought to implement international support for all people with disabilities. The document sets out a definition of disability that to date has received the most international agreement compared to all other documents produced by the UN.

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (UN Convention on the Rights of Persons with Disabilities, 2006)

The Measuring Health and Disability in Europe (MHADIE) consortium further developed the definition of a person with a disability proposed by the UN Convention by suggesting that disability in general should be defined as follows.

"Disability is a difficulty in functioning at the body, person or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors." (Leonardi, Bickenbach, Ustun, Kostanjsek and Chatterji, 2006)

In Canada a group working towards setting research priorities for childhood disability held a workshop during which the definition of what is meant by disability was addressed. The consensus reached at the meeting suggested that the following definition captured the concepts that members felt were important in order to define disability in childhood.

"Childhood disabilities refer to differences in children's development or current functioning (in any or all of the spheres of physical, cognitive, affective, social, communicative, or sensory function) resulting from interactions of conditions that are intrinsic to the child, and environmental factors which may present barriers to full development and function. Such conditions (intrinsic) and the interactions of these within environmental settings, including societal attitudes and values (extrinsic), present special challenges for the child and their family, as well as for institutional systems, communities, and future employers." (CIHR Opportunities Project, 2000)

One final important definition which attempts to capture the nature of disability is one set out by the World Health Organisation in their International Classification of Disability and Health which is a multidimensional coding system that aims to incorporate the psychological, medical and social models of disability. The WHO. defines impairment as:

"a loss or abnormality of the body structure or of a physiological or psychological function." (WHO, 2001).

The strength of these generalised definitions is that they are inclusive and they cover a wide domain of possible problems that children with disabilities may encounter. However, this inclusivity is also a fundamental weakness as this allows individuals with conditions that can be successfully managed with medication, such as asthma, to be included in the data collected and this marginalises the usefulness with respect to service use.

During the consultation process colleagues reached the consensus that the most useful of the generalised definitions was that offered by the UN Convention on the Rights of Persons with Disabilities (2006). Experts agreed that this definition contained all the necessary elements to accurately describe the nature of childhood disability.

Categorical Definitions

The second level of definitions that are available are those that categorise disability according to the system affected (e.g. sensory, psychiatric and intellectual). The definitions at this level are much less specified and use of such categories varies between studies and published documents that discuss disability. The following ten documents were selected from a variety of sources (international studies of disability, health, education and social care documents and published academic journals) for use in a simple quantitative analysis of the frequency of category use across studies of disability.

The World Health Organisation (2007)
Hutchison and Gordon (2005)
Evans et al (1999)
Jones et al (2002)
Cans et al (2003)
Hutchison (1999)
NHS Decision Support Tool (2007)
National Disability Study (2006)
SEN Definitions
OHIO Classification (2002)

Twenty-two categories were identified and only one document, the ICF-CY (World Health Organisation, 2007), was able to accommodate all of these. Only one of the categories identified, the movement related category, appeared consistently across all ten documents. The seeing and hearing categories were also prevalent across the documents with eight occurrences of each and six occurrences of the learning and consciousness categories (see figure 1).

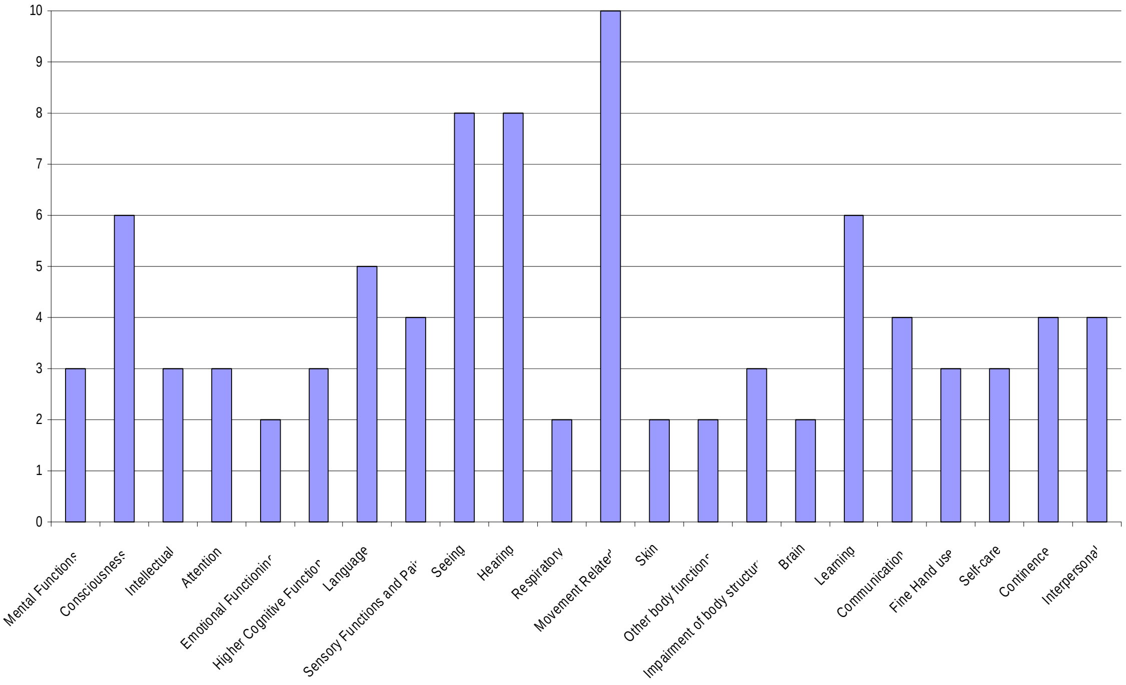

Figure 1: Graph illustrates the total number of occurrences for the twenty-two identified categories across the ten documents investigated.

The categorical definitions are not always clearly defined, however, good definitions for inclusion in the movement related category is available in both health and education literature. Movement is defined on a continuum which ranges from the individual being independent to being fully dependent on a carer for their needs (Department of Health, 2007). The categories for seeing and hearing are also clearly specified and these definitions were available across the health, education and social care domains. These definitions set boundaries for inclusion. The definition for seeing for examples states:

“Levels of visual impairment are: slight if <6/7.5, 6/18 or better, visually impaired if less than 6/18 to 6/60, severe if less than 6/60 to 3/60 and blind if less than 3/60 to no light perception or visual field.” (NEPHO, 2003).

While the definition for hearing specifies:

“Hearing impairment: mild = 20-40dB, moderate = 41-70 dB, severe: 71-95dB, profound: ≥96dB. Terms used to describe children with severe impairment: hard of hearing = moderate to profound acquired hearing impairment, deaf = severe to profound congenital or early-onset hearing impairment, Deaf = culturally deaf, use sign language and member of Deaf community.” (Hindley, 2005)

All three of the most prominent categories have clearly defined eligibility criteria that facilitate easy identification and inclusion of cases. This may be why these three categories consistently appear across all or most of the documents.

The learning difficulties category which also demonstrated a high prevalence across the ten documents is also clearly specified particularly in Education based literature with clear definitions being proposed by the Special Education Needs criteria and by researchers in education. According to these definitions learning disabilities are diagnosed primarily on the child’s intelligence scores and using disparities between intelligence and actual academic performance.

All four of the categories discussed in detail here share common features, they are all well specified, all have some form of clear measurable criteria and they all have a consensus across the three domains. The categorisation of children with disability is challenged by some professionals working in this area.

During the consultation process, one of our consultants suggested that:

“There is an underlying assumption that certain conditions that fall into a certain category will have certain needs. Two families with each with a child with the same condition but with different employment, lifestyle, and family members are not likely to have the same needs.” (Colleague 5)

It was agreed that professionals are reluctant to categorise children, but if data which readily permits audit is to be generated and used in the planning of services for disabled children, then it is necessary that local authorities have an awareness of how many children have disabling conditions. In additional, it is vital to understand how many of these children need services and what kind of services they require in order to support their everyday living.

Following consultation with colleagues most agreed that it was categorical definitions that were deemed to be the most useful when addressing prevalence of childhood disability and that data based on categories enables information to be gathered that will assist in the planning of services. Once colleague stated:

"…as a local authority manager my main interest will always be what it can tell me about the need for services. Therefore I lean towards categorical definitions because they come closest to indicating the type of assistance children might require." (Colleague 4)

Individual Condition Definitions

The third level of definition is that of individual conditions. These definitions focus on capturing a specific group of individuals and providing highly detailed information that can be used to inform about service use, possible co-morbidity and can provide detailed prevalence data for the conditions in question. A total of 118 different definitions of types of disability were collected from the systematic review, one example of this type of definition is:

"Cerebral Palsy – is a nonprogressive disorder of posture and movement caused by a defect or insult to the central nervous system. Basically it is a static encephalopathy with a delayed developmental presentation. Although it may appear to worsen, changes are actually the result of the deficits becoming more obvious as the child grows and matures over time. The area of the brain affected or damaged is directly reflected by the resulting disabilities. Although it is a motor disorder, it can also be associated with additional developmental disabilities such as cognitive impairment, depending on the degree of brain damage that has occurred. There is no cure for this lifetime condition, but therapy, education and technology can maximise each child's potential by improving functional abilities and quality of life." (Wilson Jones et al, 2007).

The disadvantage of collecting data using individual conditions definitions is that these are extremely exclusive and if used for audit purposes they can only inform on the prevalence of one condition. Another disadvantage of collecting prevalence figures in this way is that some cases may be counted more than once especially if a child has more than one condition. A good example of this comes from children with mobility problems, often these problems will be accompanied with a co-morbidity of a learning disability. This means that the same child will be coded twice, once under each condition. When using individual definitions it is important to ensure that children counted are only included once or this may skew the prevalence data and lead to misleadingly high figures. Contrastingly some children may not be counted at all if they have not yet received a formal diagnosis.

Summary of findings: Identification of definitions of childhood disability

- **Disability can be defined on three levels; generalised, categorical and individual conditions**
- **During consultation colleagues agreed that the most useful generalised definition of disability is that set out by the UN Convention on the Rights of Persons with Disability**
- **Each level of definition has its own advantages and disadvantages**
- **The most useful for audit purposes is the categorical level**
- **Categories are not consistently measured across current data collections**
- **Only one document, the ICF-CY, was able to accommodate all the categories uncovered during the project**

5. Developing an ‘integrated’ coding tool

The results from the review and from the consultation exercise regarding issues related to the data collections suggested that in order to overcome current problems with comparing data sets, the development of an integrated coding tool which could be used across the domains of health, education and social care had the potential to relieve and overcome these difficulties.

An investigation of current methods of collecting data revealed organisational biases towards coding systems with only data relevant only to specific agencies being stored, e.g. the use of the International Classification of Diseases (ICD) for health data. The difficulty with using such a system across organisations is that the codes are not that relevant to the domains of education or social care where medical diagnosis does not form the basis of the assessments of needs. If data is to be effectively shared between organisations the data that is collected needs to be relevant to all parties. One way of ensuring such relevance is to adopt a coding system that permits all three domains to collect information that is relevant to their areas of need while maintaining accessibility for the merging of data sets. Investigations revealed that a coding system that explores the classification of functioning, disability and health (ICF) had been revised and updated by the World Health Organisation. ***In 2007 a version of the International Classification of Functioning, Disability and Health developed specifically for use with children and youths was released, the ICF-CY.***

The ICF-CY is published with a number of specific aims;

- to resolve issues of data comparison both across countries and agencies that deal with health and health related issues,

- to provide a common language that can be used in a multidisciplinary setting including improving communication between professionals and the public (or in the case of this project to improve communication to parents and children with disabilities) and
- to provide the basis for systematic coding of health information (World Health Organisation, 2007).

The ICF-CY classifies disability and health related issues in two parts; functioning and disability, and contextual factors. Each part has two components,

- **Functioning and disability** includes the components ***body functions*** (the physiological and psychological functions of the body systems) and ***structure*** (anatomical parts of the body such as organs, limbs and their components) and activities (tasks or actions executed by the child) and participation (the involvement of the child in everyday life situations),

- **Contextual factors** includes the components of ***environment*** and ***personal factors*** (the physical and social aspects of the child's life, this includes the attitudes of people connected to the care of the child).

The other advantage to the ICF-CY is its flexibility to permit coding across a continuum for disability, the classification is organised to allow professionals to score children between 0 and 4 depending on the extent of their impairment or difficulty. A code of 0 is equal to no problem (0-4%), 1 is equal to a mild problem (5-24%), 2 is equal to a moderate problem (25-49%), 3 is equal to a severe problem (50-95%) and 4 is equal to a profound or complete problem (96-100%). This scale is used across all four components with the exception that scores can be both positive and negative for the environmental components. This is done to allow professionals to acknowledge any supporting factors in the child's environment as well as any factors that have a negative effect and introduce further barriers to the child which restrict normal functioning (World Health Organisation, 2007).

The other key feature of the ICF-CY is its capacity to allow professionals to code information regarding children at a depth appropriate for their purposes. For each component (e.g. body structures) it is possible to add a second qualifier which looks at the problem in more depth. The use of this system permits professionals to capture a holistic snapshot of the needs of any child with a disability or severe health problem, regardless of the type, that can then be used in the planning of services and assessment of needs based on the child's individual circumstances. If the data is re-examined over time the tool can also provide a developmental trajectory for the individual that clearly charts any changes to the child's condition. The structure of the ICF-CY (World Health Organisation, 2007) also permits a good basis for data collections that can be used across agencies and will permit effective audits that can inform on the prevalence of different types of disability and also the severity of such disabling conditions. However, it is important to bear in mind that the ICF-CY is a tool for exploring disability and health not a tool for performing medical diagnoses; therefore it may be necessary that this sits above or alongside other coding systems that would be used in a medical setting for diagnostic purposes.

6. Phase 2 and 3 consultation- Integrated Coding System

Following e-mail consultation in phase two of the project most colleagues agreed, at least in principle, that the adoption of an integrated coding tool such as the ICF-CY could have the potential to resolve some of the current issues with data collections. Many colleagues also agreed with the adoption of this particular coding system**.** One of our consultants wrote:

"The ICF International Classification of Functioning, Disability and Health. This is central to the learning and practice of professionals in North America and Scandinavia and much of Europe. German legislation is enshrined in its concepts. All EU research has to work from this framework. The UK is far behind."
(Colleague 1)

The same colleague presented further evidence to support this assertion by referring the research team to work undertaken in Europe which had sought to test the validity of the ICF-CY as a multidisciplinary data coding tool (Measuring Health and Disability in Europe Research Group (MHADIE), 2008). The MHADIE group presented a number of policy recommendations to the European Parliament on the 16th September 2008, included in these recommendations was the assertion that through the adoption of the ICF a common language between professionals was developed. The consortium also suggested that following their research project which had spanned three years and thirteen countries they had established supporting evidence for the utility of the ICF in harmonising data collections across both populations and sectors in Europe (MHADIE, 2008).

In order to test the applicability of the ICF-CY (World Health Organisation, 2007) individual condition definitions collected during the review of published articles from the domains of education, health and social care were mapped to the coding system in the form of a gap analysis (see appendix A). Items placed in the matrix were colour coded according to their origin, definitions from health data were coded in blue, definitions from education were red, social care was green, academic journal articles were coded in orange and DWP documents were coded in purple. In addition criteria from SEN documents, the NHS Decision Support Tool and the DWP Disability Handbook (a document that gives guidance on eligibility for Carer's Allowance and Disability Living Allowance) were also coded into the matrix. Definitions from the social care domain were difficult to locate and very few of these were included in the matrix. In order to account for co-morbidity of conditions and areas in which the definitions were not that clear cut a links column was written into the matrix, this enabled the tracking of such factors. The gap analysis revealed that; the coding system could comfortably accommodate definitions from all three domains, there were areas in which the three domains had some consensus of agreement and there were some underspecified areas in the document.

Most consultants in phase two of the project agreed with the placement of the definitions, one suggested that further work with a wider audience should be done to make sure that these were 'on spot'. Unfortunately due to time constraints of the project this was not possible at this time, however further work should be undertaken should this system be considered for adoption in the future.

Following the general consensus of agreement work on a theme analysis of these definitions was undertaken; the results of which are presented in appendix B. During the theme analysis some definitions were relocated in the matrix. Colleagues who took part in the third phase of the research agreed that the ICF-CY may have the potential to relieve the current problems in data collection in the UK. Colleagues requested further information from the MHADIE research group in particular colleagues were interested in the tools that the MHADIE had developed in order to support data collections. The research team have sought further correspondence with Dr Leonardi in Milan and this will be feedback to the project commissioner in due course.

During consultation the research group requested colleagues to address the utility of an integrated coding system such as the ICF-CY and also addressed the issue of gaps in the matrix. Some colleagues offered suggestions for how some of the gaps could be filled but not all spaces were adequately accounted for. This issue may require additional work prior to any decision to adopt and integrated framework, such as the ICF-CY (World Health Organisation, 2007) as an integrated tool. In response to our requests for feedback on the utility of the ICF-CY coding system some colleagues suggested that the current number of categories were too extensive and that in order to make the tool more user friendly it would be necessary to organise the framework so that professionals would be able to access only the areas that they needed during data coding. One colleague suggested:

"The number of categories as they stand are too numerous and would be difficult and time consuming to populate. If it were an electronic system, it could have sections and subsections so that the whole of the ICF – CY does not have to be accessed for one sub set…" (Colleague 7)

One colleague addressed the utility of the document from a medical perspective. This consultant stated:

"The challenge, it seems to me, is how this system is incorporated into day-to-day work in the different agencies. Doctors will continue to use medical diagnoses and the ICF-CY categories would not be specific enough for us, I think. Thus there would have to be some way of mapping medical diagnoses (currently ICD 10 by and large, but gradually moving to SNOMED) onto the ICF-CY." (Colleague 6)

Clearly, further work addressing the utility of the ICF-CY (World Health Organisation, 2007) needs to be conducted to ensure that this method can successfully overcome the difficulties discussed with previous data collections. However, the initial scoping work during which definitions were mapped from across the three domains suggests that this framework may be useful as a bridging tool between current data sets. Appendix A demonstrates the areas of current agreement in the definitions used by the three domains, therefore provided that appropriate steps are taken to account for issues of double counting, e.g. where the same child is listed more than once between organisations, and issues related to the representativeness of the data, e.g. whether registration was voluntary on the part of the parents or not, it is possible to begin work to draw some of the current data sets together with some consensus regarding the definition and criteria. Examples of this are:

- Language, code B167 (see appendix A), where it is possible to bring together definitions of language difficulties from Health, Education, DWP documents and published academic journal articles.
- Learning and applying knowledge, code D1, where it is possible to bring together definitions from Health, Education, Social Care and published academic journal articles.
- Mobility, code D4, where the definitions from Health, Education and published academic sources reach agreement.

Further investigation exploring the use of data in this way is required to ensure that figures generated remain accurate during the re-categorisation process.

Summary of findings: Developing an integrated coding system

- The ICF-CY is a child specific multi-agency coding system
- The ICF-CY has a research basis
- In Europe recommendations for the adoption of the ICF-CY as a multi-disciplinary coding system have been made
- It was possible to map the definitions of disability drawn from the education, health and social care to the ICF-CY
- Analysis of the results revealed both areas of agreement between the three domains and gaps in information that need to be addressed
- Utility of the ICF-CY in the domains has yet to be tested in the UK

7. Discussion

Existing data sets that contain auditable data on childhood disability have a limited capacity to be used in the planning and commissioning of services. Figures that are available can be used to give an estimate of prevalence figures at both the local and national levels. However, these figures should be used with caution as all current data collections have both strengths and weakness which need to be taken into account prior to use.

It is positive that all local authorities and many service providers have some form of data collection; unfortunately these are all at different stages of development at this time. In order to begin to resolve the data issues it is important that professionals now begin to consider their data collections in a different way and begin to think strategically about the usefulness of such data sets in the future. Scoping work undertaken during this study suggests that one resolution to the current problems would be for professionals to begin to work together to establish consistency in the way that data regarding childhood disability is collected and stored. Further to this it is important that authorities begin the foundation work to agree on ‘integrated’ definitions and criteria that will be applied in such collections.

Current disparities between definitions and criteria are unhelpful on a number of levels:

1. Disabled children and their families do not have a clear idea of which, if any, services that they are entitled to access.
2. The lack of consensus within authorities and their services limit the usefulness of the data that they collect and therefore restrict the ability to plan and commission services according the levels of need in their area.
3. The lack of national consensus regarding definitions of disability and the types of data that should be collected serve to emphasise the problems on a local level.
4. Although local disability registers were established to enable collection of such data, problems regarding resources such as funding and staff prevent local authorities from making good use of this system. The lack of clear information regarding the purpose of such registers also deters parents from registering their children’s details.

Until the issues regarding the disparities in the data collections are resolved, it is possible for there to be a ‘stepped change’ approach to developing an agreed, integrated approach for collecting data. Health and local authorities should be able to match their current data sets across the proposed integrated framework – the ICF-CY. This has been demonstrated in this projects earlier gap analysis (appendix A). To do this health and local authorities can compare existing data categories and definitions and combine the data in areas which show overlap between collections. In order for this to work successfully it will be essential to provide a method for identifying or tracking individual cases to ensure that those defined with disabling condition are counted only once or at least acknowledged as having conditions that span a number of domains or this will skew the final figures. For this it would be useful to establish unique identifying numbers or use numbers from birth certificates as these will only pertain to one person. That way it will be possible track children through the system and ensure that figures are accurate.

8. Recommendations

1. In order to overcome the potential vulnerabilities of current data set and to develop a comprehensive approach to data collection, it is recommended that a developmental ‘stepped change’ approach is taken to resolving data collection issues. This development work should extend across the domains of education, health and social care. It is recognised that an immediate whole system change is inappropriate, given the extent of the issues raised

a. To enable the initial stage of the process, it is recommended that commissioners, providers and professionals from across children’s services should collaborate to map current databases in use and agree areas of consensus. This could be done on a local or regional basis
b. There is also a need to identify possible areas where double-counting could occur, and to put structures in place to assist in reducing the occurrence of this. For example, a tracking or individual case identification system.
c. It is vital for commissioners, providers and professionals working in children’s services to consider the variability and reliability related to current data collections of childhood disability and begin work to establish consistency in the way that data is collected and coded data.

2. An integrated framework should be developed and agreed across the domains of education, health and social care at a National level. This would steer the successful implementation of the ‘stepped change’ approach suggested. The ICF-CY should be considered as an option for providing this framework due to its international agreement, its research base and its previous success in harmonising data collections in Europe.

3. Pilot studies investigating the utility of the ICF-CY should be undertaken across five local authorities (these should include one in the London area) in England. This will enable professionals in education, health and social care to establish what this coding system means for them and assess the impact that this framework has on harmonising the data sets across domains.

4. In order to overcome the issues of double counting a method of identifying children should be established. There are current plans to develop unique identifier numbers for children, however, one alternative may be to collect birth certificate numbers.

5. It is important for the recommendations and the possible use of the ICF-CY are considered by the project group overseeing the implementation of the Child Health, Maternity and CAMHS Care Records.

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