

Indicators of Health and Well-being for Children and Young People with Disabilities: Mapping the Terrain and Proposing a Human Rights Approach

Prepared under Australian Research Alliance for Children and Youth (ARACY) Seeding Grant 2009-2010

Health and well-being indicators for children and youth with disabilities

Convenors

Professor Gwynnyth Llewellyn, Faculty of Health Sciences,
Director, Australian Family and Disability Studies Research Collaboration
(AFDSRC), University of Sydney

Associate Professor Helen Leonard, Senior Research Fellow
Division of Population Sciences, Telethon Institute for Child Health Research
Centre for Child Health Research, The University of Western Australia

Acknowledgements

Authorship of this paper began under Dr Vikki Fraser with significant consultation with Rosamond Madden and input from Dr Anne Honey, Professor Gwynnyth Llewellyn and Professor Eric Emerson. Authorship of the Appendix began with Melissa O'Donnell and Rebecca Glauert with later contributions from Rosamond Madden and Professor Eric Emerson. We acknowledge the extremely valuable feedback on earlier drafts from all members of the ARACY Seeding Grant collaboration and trust the final paper fairly reflects their combined expertise.

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1.0 Introduction

This review of the literature has been prepared in the context of a research study which aims to investigate the development of a robust set of indicators to measure the health and well-being of children and young people with disabilities. Two approaches are being used in the study to inform the development of a set of indicators: the first approach takes a human rights perspective and utilises the United Nations (UN) Conventions, specifically the UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD) to conceptualise items relevant to children and young people with disabilities; the second approach is consumer and advocacy oriented and involves children and young people aged between seven and twenty-four years of age in focus groups discussing the topic of their health and well-being. This study arose against the background of children and youth with disabilities in Australia faring poorly compared to their non-disabled peers, a situation that is in direct contravention to Australia's obligations under human rights conventions. Progress on developing indicators to monitor health and well-being for children and youth has not extended to those with disabilities and there is reason to believe that additional indicators may be appropriate.

In particular, this review of the literature aims to develop an understanding of how studies into well-being have been formulated, what ways exist already to measure child health and well-being, and how health and well-being might be addressed in the context of children and young people with disabilities. As such, the review examines developing a framework for indicator development from a human rights perspective. By doing so, the literature review suggests a model that can be used to measure health and well-being across a broad population, but also disaggregated to specifically address the well-being of children and youth with disabilities in a way that is meaningful to them. In the context of this review we define people with disabilities as people:

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. (United Nations, 2006, Article 1).

In the context of international debate about the concept of well-being (and including concepts such as quality of life, happiness, subjective well-being) the study utilises a broad, rights based vision of well-being, consistent with Sen's views on well-being. Sen (1985) proposed that "the central feature of well-being is the ability to achieve valuable functionings" (p. 200) and he argued for "seeing well-being in terms of functioning vectors and the capability to achieve them" (p. 203). Sen's approach is widely accepted, underpinning the Human Development Index (United Nations Development Program (UNDP), 2009); it could be said that CRPD represents a list of capabilities/functionings relevant to (and defined by) disabled people. As such, well-being is taken as being an overall experience of life, including but not solely defined by health or income status, and able to be understood by the level of experience of a range of human rights and opportunities. This position underpins the investigatory research study into health and well-being indicators for children and youth with disabilities and directs the following review. The scope of this review does not include literature on quality of life of children and young people with disabilities, much of which (although not all by any means) primarily incorporates parent, family or professional perspectives. While recognising the importance of that approach, the study and hence this review is primarily concerned with the question of the potential utility of the two human rights instruments to inform development of a set of indicators of health and well-being for children and young people with disabilities.

2.0 Background

Systems for monitoring well-being ideally involve both (a) measuring overall social progress and (b) identifying inequities (social injustices) in the

distribution of well-being (for instance, the life expectancy of Indigenous people in Australia compared to other Australians) (e.g. UNDP, 2000; Australian Institute of Health and Welfare (AIHW), 2005).

All approaches to measuring well-being reflect an underlying theory, framework or philosophical position. In recent years human rights frameworks and instruments have been increasingly used as explicit organising frameworks. The value in doing so is threefold. First, many human rights frameworks are closely and explicitly associated with strong philosophical underpinnings (e.g., Sen, as quoted above). Second, they are relevant to current national obligations and commitments. Finally, they are usually developed through more participative and deliberative processes (rather than just expert opinion), notably in the recent case of the CRPD.

Since the development and ratification by a majority of countries of the CRC, measurements of quality of life and well-being have increasingly been directed toward children, and the well-being of children and young people is now of major international importance (AIHW, 2010; Ben-Arieh, 2008; Rees, Bradshaw, Goswami, & Keung, 2010). Following the 2007 UNICEF report into the state of children's well-being in OECD countries, many countries have produced 'State of the Nation's Children' style reports. Just as the CRC continues to provide a responsibility to consider the well-being of children, as well as a framework for doing so (Ben-Arieh, 2006; Bradshaw & Noble, 2006), we propose that the CRPD also be similarly used in considering the well-being of children and young people with disabilities.

Refinement in reporting on children's well-being is now occurring for example by disaggregating data in relation to particular contexts or situations such as ethnicity (ARACY, 2008; AIHW, 2005, 2009b; Bradshaw & Noble, 2006; UNICEF, 2007), age (ARACY, 2008), and wealth (Bradshaw, Hoelscher, & Richardson, 2007a, 2007b). Such distinctions have been particularly useful in highlighting similarities and disparities across economic situations according

to Bradshaw, et al. (2007a, 2007b), as well as highlighting distinct areas of disadvantage experienced by particular groups. For example, the ARACY Report Card (2008) into children's well-being in Australia identifies the ways in which distinct disadvantages in well-being are experienced in indigenous communities, and therefore is useful in identifying potentially 'high-risk' groups and a necessary direction for policy focus.

Traditionally, however, many of these well-being frameworks have used childhood disability as a marker of poor health status (and consequently poor well-being) or have omitted altogether considerations of disability, rather than considering children with disability as a group for whom a distinct consideration of well-being is merited. Thus, extant reports tend to rely on a 'top down' method of indicator development which privileges existing modes of knowledge and does little to challenge the silences that may exist for example around traditionally excluded populations (or groups), such as children with disabilities or chronic health conditions.

Two perspectives hold sway in discussions on children and young people with disabilities. The first is that of their families. While acknowledging the importance of family to children and young people with disabilities, a critical issue to be addressed in the study is the examination of health and well-being from the perspective of young people in their own right (as is the case in state-of-the-nation's style report cards for children more broadly). The other perspective is that relating to impairment, chronic health condition or illness in which the child or young person's identity is primarily viewed through the lens of their 'condition'. The challenge in the study, and in this review, is to find robust ways to operationalize "a Report Card" about the health and well-being of children and young people with disabilities which acknowledges the lives of children and young people as worthy in their own right. To do so, we have chosen to use an international human rights perspective and to explore the views of children and young people with disabilities about their health and well-being.

An issue in child indicator research attracting increasing attention is whether children themselves ought to be involved in determining indicators of relevance and in contributing to the construction of measures used in state of the nation's children reports and other reports on children's well-being. Currently there is a privileging of one perspective, that of adults, which may (or may not) effectively silence children's views of their world. This concern has particular relevance to developing an indicator set for children and youth with disabilities whose experience of the world may differ quite markedly from that of their non-disabled peers, and who themselves are not a homogeneous group, but one in whom variations in experience need to be appreciated.

It may be the case that the different experiences of children and young people with disabilities necessitate different ways of thinking about and measuring their well-being. This, coupled with the overall exclusion of children and young people's voices from developing well-being measures, means that virtually nothing is known about how children and young people with disabilities experience and understand well-being for themselves, and how concepts of well-being of and for children and young people with disabilities may impact on child indicators of health and well-being more generally. In the context of the co-informing CRC and CRPD, it is important to see how this situation can be remedied in the development of a set of indicators for the well-being of children and youth with disabilities.

The CRC and the CRPD provide key policy goals and hence a framework in which to outline key indicators for determining the state of children in signatory States. Many of the state of the nation's children reports use CRC articles as frameworks to identify well-being indicators in extant data collections (ARACY, 2008; Ben-Arieh, 2006; Bradshaw, et al., 2007a; UNICEF, 2007). However little has been done to date to utilise the CRPD to this same effect. For this reason, in this literature review we identify potential indicators associated with each of the conventions, as well as reviewing how

these indicators have or have not been used in other child well-being studies, including studies concerning children with disabilities.

This study thus seeks to expand on the existing literature on the well-being of children and young people by:

- explicitly exploring the well-being of children and young people with disabilities,
- using the CRPD as well as the CRC as a framework for indicator construction, and
- seeking the views of children and young people with disabilities in formulating sets of meaningful indicators.

3.0 Developing Indicators

This section will focus on the ways in which indicators are generally developed. The following section will apply this literature to existing frameworks, studies and the two previously mentioned conventions.

A number of key principles have been identified as informing the development of good indicator sets. According to Moore (1997) there are 13 key criteria for the development of indicators. These criteria are:

1. Comprehensive coverage
2. Age inclusiveness
3. Clarity
4. Positivity and negativity
5. Depth, breadth and duration
6. Common interpretation
7. Consistency
8. Anticipation of the future
9. Rigorous methods
10. Geographic focus
11. Cost

12. Reflexivity regarding social goals

13. Ability to adjust for demographic trends (Moore, 1997:37)

These criteria not only allow for the development of indicators, but stipulate the importance of potentially developing data sets (demonstrated through criteria 9, 10 and 11) that allow these criteria to be met. This is important to note as more recent indicators tend to focus on existing data sets only. Moore (1997) argues it is necessary to consider ways in which existing indicator sets can be reinvigorated in order to produce higher quality data that is better indicative of the position of children in society.

The UNDP provides an alternative set of criteria for assessing the quality of indicators developed. These criteria state that indicators must be based on research, but also be:

- Policy relevant, and therefore able to be influenced by policy action
- Reliable and able to be used by different people with consistent results
- Valid, based on identifiable criteria and able to measure that for which they were designed
- Able to be consistently measured over time and therefore able to be used longitudinally
- Able to disaggregate in order to focus on social groups, minorities etc
- Able to separate the monitor and monitored to minimise conflicts of interest (UNDP, 2000, Box 5.1)

These criteria help to minimise some of the potential biases and conflicts that may emerge through indicator sets. Further, the relationship between policy action and indicator sets, as well as the other criteria stipulated, may provide a way for indicator development to answer Moore's (1997) call that indicator sets be constantly reinvigorated.

The criteria outlined by the UNDP are similar in form to those developed by the AIHW. The AIHW identified eight key criteria for the development of good indicator sets. These criteria are then further defined by measures of how

indicator sets and resulting data should be utilised by research. The criteria are outlined thus:

1. Validity
2. Relevance
3. Applicability across groups
4. Reliability
5. Sensitivity
6. Robustness
7. Clarity and ease of understanding
8. Data support (either available or collectable) (AIHW, 2005:406)

Once indicator topics are selected, the AIHW further stipulates that three main measures should be applied to each topic:

- Measures of average or level (for instance average income);
- Measures of distribution or inequality (for instance, income distribution across age groups or population groups such as people with disability, or geographic regions); and
- Measures of disadvantage or social exclusion (for instance poverty) (AIHW, 2005:5).

A decade after Moore (1997) reported her criteria, Bennett and Lu (2007) highlighted the fact that societal and cultural contexts impact on the choice of indicators of well-being. As an example, current indicator sets tend to favour indicators of health and material well-being as indicators of overall well-being. This is potentially influenced by a societal trend toward improving health status worldwide, and an overall belief that materiality is inherently interconnected with health and well-being. There is evidence that supports the interconnectedness of wealth and well-being, however there is not necessarily a direct correlation between the two (UNICEF, 2007). In particular, while we know that low and low to middle income countries experience particularly strong differences in population well-being, there is little difference in well-being status between high income level countries. However, there is a significant difference at the population level in high income countries, which

can be statistically linked to unequal distribution of wealth within a country (WHO, 2008; Wilkinson & Pickett, 2009). Income status alone cannot be taken as the sole measure of well-being and data must be able to account for the role of the relative *distribution* of wealth and resources (including education, community and so on) among a population in order to fully demonstrate a correlation between wealth and well-being. Likewise, despite the existence of census data on concepts such as spirituality, this generally is absent from or has low priority in Western indicator sets (Daaleman & Frey, 2004; Willeto, 2007). As these two brief examples show, current indicator sets appear influenced by societal priorities, privileges and contexts. However, it is also recognised that there is no singular indicator set that can or should stand as a proxy for overall well-being (UNICEF, 2007). In recognition of this, a small number of indicator sets have attempted to provide a more holistic view of overall well-being, such as the AIHW (2003) welfare indicators, which examine Healthy Living, Autonomy and Participation, and Social Cohesion. These are further examined in Table 2.

The use of indicator data in developing, informing and influencing policy (Ben-Arieh, 2008; Bradshaw & Noble, 2006; Hanafin & Brooks, 2009; Pollard & Lee, 2003) is a critical consideration and particularly so given Bennett and Lu's (2007) assertion that cultural contexts impact on how well-being is conceptualised and the indicators chosen to measure well-being. Developed indicator sets may be constructed to reflect the political goals of a given society, including the appearance of compliance with international policy directions – such as the Declaration of Human Rights and the Convention on the Rights of the Child (see for example National Children's and Youth Law Centre & Defence for Children International (Australia), 2005). As pointed out by a number of authors, such influence over indicator development can become problematic in providing an adequate picture of the well-being of children and young people at the population level (Bennett & Lu, 2007; National Children's and Youth Law Centre & Defence for Children International (Australia), 2005). As Bennett and Lu (2007) maintain, those in the policy area tend to prefer the development of indicator sets which help them demonstrate achievement of their goals. Needless to say, it is surely

preferable to have a model of developing indicator sets that transparently direct policy to more effectively meet the well-being needs of children and young people.

Bennett and Lu (2007) also highlight a major assumption in current studies that each variable has equal weight with respect to overall well-being. Similarly, they identify the issue that overweighting of particular indicators can cause, for instance via double counting, particularly within indicators of material well-being. In order to address such problems, other indicator sets have been developed based on principles that acknowledge both the political nature of indicator data and the impact that this has on weight attribution. In this regard, it is important to acknowledge, as has been done by some studies (AIHW, 2005; UNICEF, 2007), that indicator sets must be policy relevant, but not become policy driven. A relevant example here is the recently released AIHW Bulletin (2010) *Health and Well-being of Young Australians*. This Bulletin reports on the key national indicators that will inform the forthcoming report titled *Young Australian: Their health and well-being* scheduled for release in May 2011. The 71 key national indicators are based on the National Health Performance Framework (NHPC, 2001) and are similar to the indicator framework used in the report *A Picture of Australia's Children* (AIHW, 2009b). In addition a small number of additional indicators are proposed, the feasibility of which are currently being investigated.

UNICEF (2007) highlights the issue of the role of data source in contributing to weighting issues. As they highlight, focussing on existing measures, such as poverty line data, to measure indicators “presents only a partial picture” (UNICEF, 2007:6). This is a particularly important consideration when developing population level indicator sets for cross-national studies. As such, it is necessary to develop methods for creating indexes and indentifying indicators that minimise political, cultural or societal biases and over-weighting of different issues. In Table 1 we present a grouping of indicators according to the particular constructions of the CRC and CRPD, and acknowledge that this privileges the human rights frameworks upon which these conventions are based.

3.1 Using the CRC to underpin indicator development

Bradshaw and Noble (2006), Bradshaw et al. (2007a) and others (ARACY, 2008; AIHW, 2008; Ben-Arieh, 2006; Richardson, Hoelscher, & Bradshaw, 2008; UNICEF, 2007) emphasise the importance of developing indicators for measuring the well-being of children that refer to and are based in the CRC. This approach has been purportedly taken up in the majority of large and small scale reports into child well-being to date. As Bradshaw, et al. (2007a) indicate, well-being studies generally are rights based studies, due to the principles of development, best interests, and non-discrimination that are usually at the heart of such studies. The authors indicate a range of CRC Articles which well-being studies tend to address, however, as has been done in other studies (see ARACY, 2008; Bradshaw, et al., 2007a, 2007b; UNICEF, 2007), it is desirable to utilise indicators that are specifically drawn from human rights conventions in their entirety. A particular challenge is to utilise the Articles of the CRC (and in the research study currently underway also those of CRPD) incorporating the criteria for a good indicator set as proposed by Moore (1997) or AIHW (2005) at the same time as recognising the potential need to develop new data collections to meet indicator requirements, rather than omitting indicators relevant to the UN conventions due to a lack of data.

3.2 Child and Young Person Involvement in the Development of Indicators of Well-being

3.2.1 Rationale

Numerous authors have emphasised the necessity of including children and young people actively in the development of indicators of child well-being (for example Ben-Arieh, 2005; Fattore, Mason, & Watson, 2009). Ben-Arieh (2005) in particular argues that child well-being studies that do not base their indicators, at least in part, on indicators gleaned from interactions with children and young people cannot claim to be based in the CRC. The CRC

explicitly outlines that children have the right to be heard and to express themselves to others about issues that affect them and Ben-Arieh argues that:

Even if children are granted only partial legal and civil rights and the ability to participate in decision making about their lives, then they should participate at least in the same proportion in the study of their well-being, especially since it bears so much influence on them. (Ben-Arieh, 2005: 575)

Such a view is reflected by children's advocacy groups, including the NSW Commission for Children and Young People. This body has produced a number of resources for involving children and young people in research (see NSW Commission for Children and Young People, 2005) including one derived from a think tank focused on researching children's well-being with their participation (Priest & Davis, 2009). This work emphasises that children need to be acknowledged as knowers in the contexts of their lives, and addressed as such by research practice. It is believed that doing so enriches data by incorporating matters of meaning to children that adult researchers may ignore, minimise, or think are not important (Priest & Davis, 2009).

Fattore, et al. (2009) also maintain that it is important to include children in developing frameworks for measuring well-being. These authors were challenged to reposition children and adults in research, but in doing so their study resulted in greater depth of focus than would have been possible utilising only the voices and opinions of adults. Asking children about well-being allowed children to emphasise the interconnected nature of well-being indicators, a perspective sometimes missing from indicator research conducted by adults only. As Fattore, et al highlight:

Children understood well-being not in terms of isolated domains but in terms of how, for example, health or economic well-being manifested in certain types of relationships or aspects of relationships (well-being as the need for care when ill) or as certain types of emotions (e.g., feelings of shame when not having socially perceived cultural items). (Fattore et al., 2009:62)

This is an important consideration, as it reemphasises the importance of more 'human' based understandings of well-being, and the interconnectedness of aspects of human experience. Incorporating the voices of children into the development of well-being indicators that are drawn from the CRC and CRPD may highlight the importance of the interconnection of various CRC and CRPD domains into an overall picture of well-being. In Table 1 we propose a particular way of grouping well-being indicators derived by combining the CRC and CRPD. It should be recognised that this grouping is the product of able bodied adult researchers, and may not remain salient for disabled children and youth.

In sum, there is benefit in actively utilising the voices of young people in well-being studies. In the first instance, including the voices of young people is a fundamental aspect of the CRC (Ben-Arieh, 2005). Secondly, as is particularly emphasised by Hanafin and Brooks (2009), among others (NSW Commission for Children and Young People, 2005; Priest & Davis, 2009), young people may pick up on areas of importance or consideration that adults may overlook or misunderstand due to differences in the social and cultural contexts of children and adults. Such a consideration is particularly important when considering what indicators might be studied and what data collected (Hanafin & Brooks, 2009).

3.2.2 Studies including children's perspectives

A number of well-being studies have used, either in part or in entirety, the voices and feedback of young people to discuss well-being and health in child and youth populations. Furthermore, a small number of studies have utilised these voices in the development of a set of indicators that 'fully' attest to the well-being experiences of children and young people (for example Fattore, et al., 2009; Hanafin & Brooks, 2009). However, despite this, major well-being studies are reliant on administrative data to come to an understanding of the state of children across the population (Lippman, 2007; Pollard & Lee, 2003). Of the four major child well-being indicator frameworks discussed in this review (see Table 1), only one actively engages data gathered from young people themselves. Bradshaw, et al (2007a) utilise existing data from young

people in order to ascertain the state of child well-being across OECD countries. However, as the authors note, such use is limited at best, due to a lack of data sources in some areas (Bradshaw, et al., 2007a). Recently, Rees, et al. (2010) released the first report of a national survey of young people's well-being in the UK which is part of a program of research into young people's well-being with "a strong focus on gathering views and information from young people themselves" (p. 7).

Hanafin & Brooks (2009) highlight the importance of considering the voices of children in designing and conducting well-being research, however mediate this by emphasising a need to also consider 'adult' perspectives and therefore existing sources for well-being indicators. As such, in developing a report into the state of well-being for Irish children, the authors employed a variety of strategies to develop a key set of indicators for measuring children's well-being, whilst also ensuring that indicator sets were able to fit within the criteria of: comprehensiveness, age inclusiveness, dual polarity, reflective of social goals, objective and subjective, and accounting for both well-being and wellbecoming (Hanafin & Brooks, 2009). This study is particularly important, as it highlights the value of including 'top-down' indicator development with the voices of young people to ensure that greater depth of data and understanding is reached. As Hanafin & Brooks note:

Children and young people also identified 'values and respect' as being important to them and, again, it was not possible to identify a data source on this indicator area for the *State of the Nations Children* report.

Following discussions between the Office of the Minister for Children and Youth Affairs and the Principal Investigator for the Irish HBSC Survey, however, questions relating to both these indicator areas were included in the 2006 HBSC Survey in Ireland... (Hanafin & Brooks, 2009:37)

What is particularly important about this comment is that it demonstrates that utilising an approach where consensus is formed through combining the thoughts and ideas of young people with 'top-down' models of indicator development can highlight key areas where data sources need to be created. It is particularly noteworthy that the areas identified by Hanafin & Brooks

(2009) as being important to children but overlooked by both adult investigators and the existing data sources are also areas highlighted by the CRC as being fundamental to children's human rights, and from a human rights perspective of well-being, fundamental to children's experience of well-being. Such considerations are important when considering the development of indicator sets that encompass the well-being of children and young people with disabilities.

Lahikainen, Tolonen & Kraav (2008) utilised the voices of young children to determine, rather than a set indicator framework, a way of framing subjective well-being to ensure its usefulness in studies of well-being more generally. Importantly, young children (aged 5-6) were involved through interviews, and parents were surveyed ensuring that the child was still able to take the centre of the research focus, despite the involvement of their parents and the potential for parental mediation of responses, particularly where children are so young. As Lahikainen, et al. state:

In keeping with our emphasis on the subjectivity of well-being, the children themselves were taken as the primary informants of their state, despite their young age. ...In order to posit the child as an informant, the interviewer started out by saying: "I have come here to interview you because we adults do not know what it is like to be a child nowadays. (Lahikainen, et al., 2008:72)

Interestingly, the authors do not explicitly set out to develop human rights based indicators; however the focus developed from their research fits within some of the often overlooked areas of the CRC and CRPD, in particular the area of security. Importantly, discussion of the concept of security and fear with children, as is done in the Lahikainen, et al. (2008) study, was able to uncover a range of other well-being features present in more quantitative studies based on administrative data. This was particularly true of responses relating to health and risk related behaviour discussed in the four studies outlined in Table 1. While it might be argued that a focus on such negative indicators of well-being does not fit into the best practice approaches established through other frameworks, consideration should be given to the

effectiveness of including children's voices and negative experience as ways of better fitting well-being studies to human rights models.

Curie, et al. (2008) highlight some of the important factors for gaining the voices of young people when conducting research into health and well-being. As they attest, young people are often removed from research into well-being, socio-economic position (SEP) or health status through the use of adult voices as proxy, or the reliance on adult centred data. As such, Curie, et al. (2008) emphasise the importance of providing young people, particularly adolescents, with the opportunity to self report on both individual and familial economic status in order to understand the relationship of adolescent SEP with adolescent health behaviours. Such an allowance is important when one considers the growing independence from parental influence experienced by young people socially and economically during adolescence (Currie, et al., 2008; Valentine, Skelton, & Chambers, 1998). As Curie, et al. (2008) indicate, asking children about their SEP specifically aids in understanding some of the data collected in the Health Behaviour in School-aged Children (HBSC) study. Developing data in this way is important to coming to a complete understanding of health as "a resource for everyday living", which is contingent on the family, school, peer settings and socio-economic environment (Currie & Roberts, 2004:1). As Morgan (in World Health Organization, 2004) highlights, it is important to understand that young people are not passive when it comes to decision making, particularly around health and well-being. As such, including children in discussions about health and well-being is vital to gaining an accurate picture. Likewise, although it has not necessarily been the case for the HSBC study described by Currie, et al. (2008), and for which Morgan is also responsible, adequately including young people as agents in their health and well-being reporting must also include involving young people in the development of a set of indicators for health and well-being (Morgan in World Health Organization, 2004). Such moves have already been discussed in the material presented above, with great success. It remains to attempt to develop such frameworks for identifying indicator sets for use with children and young people with disabilities.

Before turning to a practical analysis of the CRC and CRPD for their utility as frameworks for an indicator set for the health and well-being of children and youth with disabilities, the next section discusses four children's well-being reports, two international and two national, and in the accompanying table identifies the inclusion (or lack thereof) within these reports of the major dimensions of the CRC and CRPD.

4.0 Four Major Children's Well-being Reports and CRC and CRPD

Table 1 outlines the intersection of four major children's well-being reports and the two conventions. The reports have been selected as major due to their international and national nature, their scope, their role in informing other studies, and their position as population based studies. In undertaking this review, it was noted that these four (utilising particular indicator frameworks) stood out for their influence in the field, and their adherence to the above mentioned selection processes for indicator sets. Similarly, these four reports are notable in their stated basis in the Convention on the Rights of the Child. These reports are:

- *Comparing Child Well-being in OECD Countries: Concepts and Methods* (Bradshaw, et al., 2007a)
- *Doing Better for Children* (Organisation for Economic Co-Operation and Development, 2009)
- *A Picture of Australia's Children 2009* (Australian Institute of Health and Welfare, 2009b)
- *The Well-being of Young Australians: Technical Report* (ARACY, 2008)

Each clause of each Convention was considered, and relevant indicators from each of the four studies sought for inclusion in the table. For ease of representation, the clauses of the two Conventions are presented in four broad categories:

- Individual Rights
- Rights to Health and Safety
- Social Rights
- Rights to Access and Supportive Environments

Areas of emphasis across the four major reports include children's:

- protection from exploitation, violence and abuse (usually indicated through abuse data)
- protection that ensures the right to life (focus is on infant mortality)
- ensured right to inherent human dignity (focus is on subjective indicators of well-being, protection from bullying etc.)
- access to meaningful and interesting resources which assist in children's development (usually indicated through education, access to educational resources and participation in early childhood)
- ability to access appropriate health support
- provision of adequate and accessible health care services
- access to adequate food, clothing and housing
- education to the highest possible level
- encouragement to develop emotionally, physically and mentally (indicated through instances of disability, mental health problems, early childhood education, participation in sport and activity)
- treatment with respect and dignity, and ability to feel respected

Needless to say, each report contains different measures of these dimensions as a result of differences in the data sources from which responses are drawn. Children with disabilities are included only as outliers on the data scales, or as indicators of low well being (through poor health), as is the case in *Doing Better for Children, A Picture of Australia's Children 2009* and *Comparing Child Well-being in OECD Countries: Concepts and Methods*. This representation of disability as an indicator of poor well-being is also found in other well-being studies, even where indicators may appear to be inclusive of

consideration of factors for children and young people with disabilities (see for example Moore & Theokas, 2008; Moore, et al., 2008).

Numerous studies have included child and youth disability statistics as indicators of the overall well-being of a population of young people, usually through the inclusion of this data into the domains about health status (ARACY, 2008; AIHW, 2009b; Bradshaw, et al., 2007a, 2007b; Moore, et al., 2008). However, CRC and CRPD illuminate the necessity of considering not only health status, but also issues of access. Queensland Advocacy Incorporated's (2006) development of a set of human rights indicators potentially highlights some of the inhibitors to well-being that may be otherwise overlooked, for example, issues of access, participation, social inclusion and environment.

As can be seen from Table 1, there is a solid emphasis in these four reports on certain key areas. While each of the frameworks utilised in these reports are rooted in the CRC, such strong emphasis on particular areas has resulted in little or no attention being paid to other areas. Interestingly also, while the inclusion of children's direct responses to questions about their well-being elicits greater detail and ability to include information on different areas of well-being than made possible through administrative data, such a method does not directly translate into a greater inclusion of more rights based indicators. It is therefore necessary to consider the development of methods for collecting data around a more inclusive framework that enables in-depth accounts of all children's experience of well-being in relation to rights.

4.1 United Nations Conventions

As can be seen in Table 1, there are numerous points of intersection between the CRC and the CRPD. Examining each of these documents identifies areas that should, in a detailed indicator set, become key areas of focus. This section maps out the dominant issues identified by the CRC, identifying how these 'domains' have been taken up by key indicator frameworks, in order to

develop an indicator set that would adequately enable an investigation of the well-being of children and young people with disabilities.

The domains listed in Table 1 were developed through an intensive investigation of both the CRC and the CRPD to identify and engage with areas of overlap. However, it is possible that different groups or individuals engaging with both of these documents would identify different domains, or indeed group indicators differently. Therefore, the domains are indicative only. However, it is interesting to note an extensive number of domains can be identified through both conventions. It is plausible to identify each of these domain areas as integral to the health and well-being of all children, in both developing and developed countries. As such, it is possible to see how these domains and indicators could be used to inform policy makers of shortcomings or areas for improvement in the implementation of the CRC (Bradshaw, et al., 2007a, 2007b). To fully realise this goal however assumes that robust data would be universally available on all indicators. Currently, population level well-being research utilises a limited set of indicator data, omitting indicators where data are limited or non-existent (Ben-Arieh, 2006, 2008; Bradshaw, et al., 2007a, 2007b).

The next question is whether the domains represented in the CRC are adequate to address health and well-being in children and young people with disabilities. As the table demonstrates, this is not the case. While there is significant overlap between the CRPD and the CRC, a major area of exclusion for children and young people with disabilities is that of environment. Although the CRC does discuss the importance of access to resources by children with disabilities (United Nations, 1989, Article 23), this appears to be often left out of indicator sets due to perceived omissions in available data. This suggests that in developing a comprehensive indicator set for children and young people with disabilities a range of data sets, perhaps also including personal experiences of barriers and segregation, and legislative data that indicates where omissions might exist will need to be considered.

The inclusion of indicators of well-being gained from the CRPD as well as the CRC potentially provides disability relevant measures. It also raises a question about the place of indicators that treat disability as an automatic indicator of poor well-being (see for example AIHW, 2009a). A focus on issues targeting disability access and supportive environments for young people with disabilities may also enable a greater selection of data and materials, through looking at broader issues of inclusion, than such a specific focus on children with disabilities might allow at the population level – thus potentially removing the possibility of omission of disability through a lack of population level data (ARACY, 2008; Ben-Arieh, 2006; Bradshaw, et al., 2007a; Bradshaw & Noble, 2006).

Table 2 extends the analysis represented in Table 1, to map against a three dimensional framework of (i) rights to health and safety, (ii) social rights and (iii) rights to access and supportive environments (derived from consideration of CRC and CRPD as per Table 1), six major frameworks to gain some understanding of the degree to which these fit within a rights based well-being framework. From this table it is possible to see that the groupings in the six key frameworks, while largely inclusive of many of the CRC and CRPD areas of concern, pay some attention to fundamental, individual human rights but not necessarily all that are critical to the well-being of children with disabilities and young people. This is potentially important, as it may indicate a lack of consideration of potential differences of experience between children with and without disabilities, particularly with regard to experiences of dignity, access and inclusion and respect. Table 1 should be read in conjunction with Table 2, and provides a detailed breakdown of which indicators fit within which domain and key rights area.

5.0 Studying the Health and Well-being of People with Disabilities

A Federated Search¹ was undertaken to reveal the breadth of research into studies of the health of people with disabilities. This search targeted documents matching the keywords of “disability” and “well-being”. Needless to say, quality of life, and health and well-being of people with disabilities have been widely studied and are represented by case reports, life narratives, small scale studies of adult experiences of well-being, clinical studies and population based studies. The initial search revealed over 14 000 studies. This result was refined by limiting the search to full-text and ‘scholarly’² publications. Further refinement created a focus on “children” and “youth”, resulting in 341 results.

It is telling that a majority of the studies revealed focus on the well-being and health of parents or families, rather than the specific well-being needs of children with disabilities themselves. It is necessary to note that, while family context and the situations and well-being of the family unit are important, studies into the well-being of children with disabilities have tended to ask parents or caregivers to respond for their children. This is not surprising, particularly when the ‘medical’ or ‘illness’ or ‘professional’ model was paramount, however when only parents or caregivers are asked the direct views of children themselves potentially are silenced. However, there is an increasing focus on children with disabilities themselves, which tends to incorporate smaller scale or qualitative studies (for example Huebner, Brantley, Nagle, & Valois, 2002), as well as tools for developing administrative data sets that take a child focus on the well-being of children with disabilities (for example Bullinger, Schmidt, Peterson, & Ravens-Sieberer, 2006;

¹ Federated Searches involve undertaking one search of a range of databases, catalogues and resource groups within an institution or set of institutions. All materials within an institutions repository will be included in the search, thus reducing the potential for dissimilarities between search strategies as a result of different database requirements. In the case of this study, the federated search system ‘Summon’, subscribed to by the University of Sydney, was utilised.

² Including peer review

Stevenson, et al., 2006). Similarly, a large number of studies utilise adult reporting of the well-being of children with disabilities, with a somewhat smaller number actually asking children to self-report on their well-being or quality of life status (for example Bakker, Denessen, Bosman, Krijger, & Bouts, 2007; Erling, Wiklund, & Albertsson-Wiklund, 1994; Huebner, et al., 2002). As these studies, and in particular that undertaken by Erling, et al. (1994) point out, major differences exist between what children with disabilities perceive as their own well-being status, and what status their parents perceive them to have. Erling, et al. (1994) identify a possible reason for this as adults projected fears for their children's ability to participate fully in a society at later stages. Many of these studies focus specifically on children with a particular impairment or health condition (e.g., Davis, et al., 2009; Shelly, et al., 2008; Uzark, et al., 2008). Although useful, these studies by definition encompass quality of life within the context of a particular impairment or health condition rather than as proposed earlier in this paper, exploring health and well-being for all children and youth with disabilities where well-being is taken as an overall experience of life, including but not solely defined by health or income status, and able to be understood by the level of experience of a range of human rights.

Although the studies into well-being, childhood and disability are quite diverse, mirroring the expected differences between different disabilities and life experiences, there are similarities that exist between each different study. In particular, similarities exist in what is actually perceived by researchers to constitute well-being. In each of the qualitative studies, and in a number of the larger studies focussing on disability, it is interesting to note that access, participation and independence are taken as crucial indicators of well-being (for example, Colver, 2005; Kirk, 2006; Mihaylov, Jarvis, Colver, & Beresford, 2004). This highlights a disconnect between existing population well-being studies, which tend to ignore or overlook issues of participation and independence (see Table 2), and disability specific well-being studies. However, while very few existing population studies include considerations of access and independence, these indicators have emerged for consideration

from the combination of the CRC and the CRPD into an indicators framework. For this reason, such studies are discussed in depth below.

The Australian Institute of Health and Welfare has been at the forefront of investigations into the life circumstances of children with disabilities in Australia. However, as they argue, finding and disseminating meaningful information about the status and well-being of children with disabilities in Australia is often quite difficult due to the nature of research conducted into this area to date (AIHW, 2004). *Children with Disabilities in Australia* (2004) is one of the first and major studies of childhood disability and well-being of relevance to this study. This report however did not specifically utilise a set framework of indicators. Rather, the document set out to use existing population level data on children with disabilities to create an overview of this population's general status within the community (AIHW, 2004), and to identify data gaps and opportunities for improvement. Much of the data is drawn from extant administrative, survey and census based data sets which, in the Australian context favours reporting on health and economic status³. As such, these considerations heavily influence the report, and other aspects of well-being are seemingly less important. This being said, the report does emphasise the need for attention to be paid to issues of equity and access, particularly around education, for the improvement of well-being for children with disabilities (AIHW, 2004). Similarly, the report highlights the necessity of considering less 'individual specific' indicators at the population level to begin to understand contributors to well-being. As an example, the report considers as a gap in existing research, details about government spending on disability – which could potentially highlight areas of need and concern for children with disability, although such an item would not necessarily be considered a high priority for children and young people themselves.

The AIHW (2009a) report, *Disability in Australia* identifies that many people with disabilities in Australia, statistically, are not having their health and well-

³ The primary data sources for the 2004 AIHW report were the ABS Survey of Disability, Ageing and Carers, Disability Services National Minimum Data Set, other community services administrative data sets, the data from Government Income Support Programs and other generic service programs.

being needs met. Again, although this report does not specifically focus on the well-being of people with disability, it reports on the status of people with disabilities in Australia from existing data. The report identifies that people with disabilities, including children, do not experience well-being in the areas of having needs met, participation and inclusion in the community, including education and employment (AIHW, 2009a). The report utilised an existing targeted population survey (that is, general quantitative survey of people with disabilities) to identify areas of concern and needs for this particular demographic group. Reporting data on different ages identifies the shifting well-being needs of people with disabilities across the lifespan. This is a timely reminder that well-being indicators for children and young people with disabilities may need to recognise potential differences across the lifespan – as an example, access to education may or may not be as important for adolescents as it is for young children, although it would remain at some level of need for all age groups. A further issue highlighted by the AIHW (2004) report is the perspective taken on particular aspects of children’s lives. This report considers the family in the lives of children with disabilities; however it explores this concept more from the perspective of the burden of care on the family and necessary support structures, rather than the potential impact of family relationships on the well-being of children with disabilities. As has been emphasised, parent relationships, stress and feelings of control have a significant impact on parent and child outcomes, and therefore child well-being (Dempsey, Keen, Pennell, O’Reilly, & Neilands, 2009; Llewellyn, McConnell, Thompson, & Whybrow, 2005).

A study by Allan Colver (2005) emphasises participation and environment as necessary factors of consideration for the well-being of children with disabilities. Colver (2005) presents two main domains for considering well-being for children with disabilities: participation and environment, and quality of life. In doing so, rather than excluding other areas of importance previously identified, previously separate domains are incorporated into these two overarching measures of well-being for children with disabilities. As such, participation and environment includes considerations of access, function, attitudes, community life, education and recreation; quality of life incorporates

other areas, such as health, physical well-being, material well-being, rights and social inclusion. According to Colver (2005) considering well-being in this way, under a framework that emphasises environment and participation on one hand, and quality of life on the other, allows for a combination of the social model of disability and contemporary understandings of childhood that allows for a greater understanding of the specific life, health and well-being status of children with disabilities, rather than an understanding that comes from administrative or parent/carer data and (pre)conceptions of the needs and experiences of people with disabilities.

In undertaking specific studies of populations with particular disability (for example, intellectual disabilities, cerebral palsy etc.), a number of indicators for consideration have been raised. As an example, Arias, Ovejero & Morentin (2009) identify the importance of considering love as a domain of emotional well-being in disability populations. Further, they highlight the fact that although love and emotional well-being are readily considered for broader populations, little empirical work has been conducted in this area for populations with disabilities, specifically intellectual disabilities. Importantly, Arias, et al. (2009) highlight the importance and interconnectedness of other indicators of well-being important to people with disabilities, such as access and social inclusion, to indicators of emotional well-being, such as love.

In the literature on well-being for people with disabilities there is some debate as to whether or not children with disabilities actually require a different set of indicators from children without disabilities in order to determine their levels of well-being. To develop an answer to this question, Hogan, Rogers and Msall (2000) utilised measurements of health and well-being that were specific to disability (from the National Health Interview Survey and Disability Supplement) in a way that combined them with existing children's well-being indicators to determine whether or not such measures would develop meaningful population level data. Overwhelmingly, they found that the measures used reflected the similarities that exist between children with disabilities and children without disabilities, particularly in terms of the impact of parenting behaviours and environment on child well-being (Hogan, et al.,

2000). However, they also emphasised that allowing well-being indicators to focus on and privilege issues of environment and access would enable a greater understanding of the levels of disadvantage with respect to well-being faced by children with disabilities. As they note, it is important to consider the “special situations of disabled children” (Hogan, et al., 2000:1048) when developing measurement tools for well-being, as doing so would enable greater understanding of data identifying the negative effects of poverty and other factors as well as providing some opportunities to address these issues through improving situations for children with disabilities and their families.

6.0 An Inclusive Framework?

As has been shown through this map of the literature, numerous approaches have been taken to developing frameworks with which to measure well-being in children, and which might be used to measure well-being in children and young people with disabilities. Increasingly, it has been emphasised that population level data sets need to include a focus on environmental and access factors in order to adequately address the specific needs and potential disadvantages experienced by individuals with disabilities in any given society. The CRPD and CRC together speak to a consensus view internationally on the human rights of people with disabilities (including children and young people with disabilities) and children respectively and generally speaking can be used to identify well-being at population level. We have already utilised this approach to some degree (Emerson, Honey, & Llewellyn, 2008; Emerson, Honey, Madden, & Llewellyn, 2009). In our report titled *The Well-being and Aspirations of Australian Adolescents and Young Adults with a Long-term Health Condition, Disability or Impairment*, available on the ARACY website (www.aracy.org.au), we document the well-being status of adolescents and young adults with disabilities according to indicators developed from the CRPD. Data gathered from the Household Income and Labour Dynamics in Australia (HILDA) survey were utilised in this endeavour. The association demonstrated by this study between poor well-being and

overall dissatisfaction with life circumstances as compared to those in the same age group without disability indicates that utilising UN Conventions as indicator sets, against relevant population data, is an adequate method for developing a picture of childhood well-being both generally and with a focus on children with disabilities (Emerson, et al., 2009).

Our approach using CRPD as a framework to investigate the health and well-being of young people with disabilities was restricted in this instance to the data available in the HILDA data set. Potentially other data sets could be similarly interrogated using these indicators derived from CRPD and matched to data items. The Appendix included with this paper documents the preliminary work we have done on Australian data sets with a more detailed and illustrative discussion of sources in one jurisdiction, that of Western Australia. However, any approach which relies on using data collected for other purposes will always be limited to the range, depth and specificity in that data set. By default, it is quite likely that certain items that are particularly important to children and youth with disabilities will be under-represented.

In sum, this review of the literature suggests the following items need to be considered in examining existing indicator sets for children or in the development of additional items or entirely new indicator sets for the health and well-being of children and youth with disabilities.

1. The framework underpinning any indicator set needs to be transparent to enable judgement about fit for purpose.
2. The framework if restricted to available data needs to acknowledge this limitation. Preferably, new data should be collected to meet the requirements of the framework.
3. The framework will most likely need to include considerations of access, environment and participation/inclusion, three areas already identified as critically important to people with disabilities and under-represented in existing health and well-being indicator sets.
4. One framework highly likely to meet or go some way towards meeting representation of the health and well-being of children and youth with

disabilities is that composed of items derived from the CRC and CRPD documents, as well as human rights indicators already in existence (see for example Queensland Advocacy Incorporated, 2006).

Further, it is necessary to consider the potential role that children and youth with disabilities themselves might have with regard to determining what constitutes their well-being. As has already been discussed, well-being data are usually driven by adult perceptions of what is important to the healthy development of a child. While such considerations are important, Hanafin and Brooks (2009) identify that children often raise experiences and needs that are overlooked by adults. This is likely, as is articulated by Arias, et al. (2009), to also be the case for children with disabilities, who may experience a dual mediation due to their status as both children and individuals with disabilities. For this reason, considering the input that children and youth with disabilities might have into the development of a framework for measuring well-being is of vital importance.

Tables 1 and 2 demonstrate the processes leading to the development of a framework that we believe is relevant to policy and addresses the gaps in children's well-being frameworks to date. Table 1 demonstrates areas which must be addressed, and highlights the particular ways of addressing these areas, including a potential grouping of indicators. Table 2 again highlights the potential gaps, as well as emphasising the need to reconsider well-being frameworks in light of the CRC and CRPD, demonstrating a significant absence of consideration for fundamental individual rights, including experiences of equality. However, it is still necessary to consider how children themselves understand well-being, to consider whether or not such grouping is indeed appropriate.

Significantly, what is highlighted through this literature review and framework development is that key studies to date into the well-being of children at a population have laid considerable foundations for the inclusion of children with disabilities into the well-being picture. However, there is still a significant way to go and, as is emphasised by Fattore, et al. (2009), covering this distance

may require a significant shift in thinking about the data collection and analysis strategies employed by child indicators of well-being researchers. As has been demonstrated, current data sets do little to include material of relevance to indicators of fundamental individual rights, such as equality, dignity and respect, although data on these issues might be easily collected through other sources. For this reason, some consideration must be made of relevant data collection strategies to ensure that all areas of the CRC and CRPD are included when reporting on child and youth with disabilities well-being in Australia and internationally.

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Table 1: Weighting of domains and indicators in CRC and CRPD according to key rights areas, with use by other indicator sets.

| Group | Domain (Articles: CRC; CRPD) | Indicator | Use by Other Frameworks | | | | |
|-----------------------------|---|---|-------------------------|----------------|----------------|----------------|---|
| | | | A ⁴ | B ⁵ | C ⁶ | D ⁷ | |
| Individual Rights | Identity (7, 8, 15, 23, 30; 3) | Children are Respected as Individuals Children are Registered and Given a Name Children are Afforded Citizenship and Nationality Children are given recognition before the law, including adequate representation and voice in legal matters | ✓ | ✓ | | ✓ | |
| | Justice (9, 10, 12, 21, 25, 37, 40; 12, 13) | Children are protected in a way that enables their right to life | ✓ | ✓ | ✓ | ✓ | |
| | Right to Life (6, 24, 38; 10) | Children are entitled to privacy and protected from unlawful privacy infringement | ✓ | ✓ | ✓ | ✓ | |
| | Privacy (16; 22) | No action is committed against children to deny them of inherent human dignity | ✓ | ✓ | ✓ | ✓ | |
| | Dignity (2, 23; 3, 17) | Children are treated with respect and dignity, and feel respected. Children are free from restraint or unlawful imprisonment Children are protected from discrimination in all its forms | ✓ | ✓ | ✓ | ✓ | |
| Rights to Health and Safety | Freedom (;14, 18) | Children are protected from discrimination in all its forms | ✓ | ✓ | ✓ | ✓ | |
| | Protection (3, 5, 9, 11, 16, 19, 20, 21, 22, 23, 25, 32-38; 11, 15, 16, 27, 28) | The best interests of the child are of paramount concern in the development of social norms and measures Measures exist to protect children in times of crisis Children are not subjected to torture, inhuman or degrading punishment or non-consensual experimentation | ✓ | ✓ | ✓ | ✓ | |
| | Care (3, 5, 9, 18, 23, 39; 4) | Children are protected in law from cruelty Children are protected from exploitation, violence and abuse Children are protected from unsafe environments, including at work Children have access to trained professionals where appropriate in the administration of their care | ✓ | ✓ | ✓ | ✓ | |
| | Parents and Family (5, 9, 10, 18, 21; 23) | Children are able to access appropriate health support Children retain their fertility are not subjected to arbitrary medical interventions with regard to family or the ability to found a family | ✓ | ✓ | ✓ | ✓ | |
| | Health (23, 24, 25, 39; 25, 26) | Children, where necessary, have access to appropriate alternative family situations Children are provided with adequate and accessible health care and services | ✓ | ✓ | ✓ | ✓ | |
| | Security (26; 14) | Children are protected from attacks on their person or environment | ✓ | ✓ | ✓ | ✓ | |
| | Development (29; 6, 24) | Children are encouraged to develop emotionally, physically and mentally Children's developmental needs are met by society | ✓ | ✓ | ✓ | ✓ | |
| | Association (15;) | Children's links to family, parents and kinship networks are maintained Children establish friendship and kinship networks that support their identity Children establish, maintain and associate with friendship networks Children are exposed to other children in a way that is conducive to friendship | ✓ | ✓ | ✓ | ✓ | |
| | Social Rights | | | ✓ | ✓ | ✓ | ✓ |
| | | | | ✓ | ✓ | ✓ | ✓ |

⁴ UNICEF Innocenti Research Centre Working Paper, *Comparing Child Well-being in OECD Countries: Concepts and Methods*, IWP-2006-03, December 2006

⁵ OECD, *Doing Better for Children*, 2009

⁶ Australian Institute of Health and Welfare, *A Picture of Australia's Children 2009*, PHE 112

⁷ ARACY, *The Well-being of Young Australians: Technical Report*, 2008

| | | | | | | |
|--|---|---|--------|---|-------------|------------------|
| Rights to Access and Supportive Environments | <p>Expression (12, 13, 14, 17; 7, 21)</p> <p>Information (17; 4)</p> <p>Representation (17; 8)</p> <p>Independence (;19)</p> <p>Standard of Living (27; 28)</p> <p>Equality (;3, 4, 5, 6, 7, 8, 12, 23, 24, 27)</p> <p>Participation (12, 17, 23, 26, 29, 31; 3, 6, 7, 9, 19, 20, 23, 29, 30)</p> <p>Access (23; 3, 4, 9, 20, 21, 25, 30)</p> <p>Education (28, 29; 24)</p> <p>Visibility (;8)</p> | <p>Children have and know their family</p> <p>Children shall not be separated from their families against their will</p> <p>Children are able to express their views on all matters affecting them</p> <p>Children are taught to express themselves, and such expression is facilitate effectively</p> <p>Children have access to meaningful information</p> <p>Children are represented in media forms and are visible through such representation</p> <p>Children are, where appropriate, able to act independently from adults or carers</p> <p>Children have access to adequate food, clothing and housing</p> <p>All children are able to access all aspects of society and family on an equal basis with others</p> <p>Children are included in the society and social processes</p> <p>Children's participation in the home and society is supported by adequate access and environmental concerns</p> <p>Children's mobility needs are considered and enable participation in the home and society</p> <p>Children have access to cultural materials, recreation, leisure and sport</p> <p>Children have access to items in their environment, regardless of perceived or present disability or impairment</p> <p>Children's mobility needs are supported</p> <p>Children have access to resources of interest or meaning to them and which assists in their development</p> <p>Measures are taken to ensure that children have access to leisure, sport, recreation and cultural events, artefacts and spaces.</p> <p>Children are educated to as high a level as possible</p> <p>Children's education is meaningful to their full participation in society</p> <p>Children's education is able to improve their access to society</p> <p>All children, without discrimination, are visible in society, through both physical and media representation</p> | ✓ | ✓ | ✓ | ✓ ✓ ✓ ✓ |
| | | | ✓ ✓ | ✓ | ✓ | ✓ ✓ |
| | | | ✓ | ✓ | ✓ | ✓ |
| | | | ✓ ✓ | ✓ | ✓ ✓ ✓ | ✓ ✓ ✓ |
| | | | ✓ | ✓ | ✓ ✓ ✓ | ✓ ✓ ✓ |

Table 2: Comparison of key indicator frameworks by key rights areas.

| Our Framework | AIHW 2003 Framework | Bradshaw, et al. (2007a) Framework | UNICEF (2007) Framework | ARACY 2008 framework | AIHW 2009 Framework | OECD Doing Better for Children Framework |
|--|---------------------------------------|---|--|--|--|--|
| Individual Rights Rights to Health and Safety | Health & Safety Subjective Well-being | Healthy Living | Social Services Provisions | Health and Safety Behaviours and Risk Subjective Well-being | How healthy are Australia's Children? How well are we promoting healthy child development? What factors can affect children adversely? What kind of families and communities do Australia's children live in? How Safe and Secure are Australia's Children? How well is the system performing in delivering quality health, development and well-being actions to Australia's children? | Housing and the Environment Health Risk Behaviours |
| Social Rights | Family | Social Cohesion | Social Conditions Informal Support Systems | Peer and Family Relationships Subjective Well-being | How well are Australia's children learning and developing? What kind of families and communities do Australia's children live in? | Education Quality of School life |
| Rights to Access and Supportive Environments | Material Well-being Education | Healthy Living Autonomy and Participation | Informal Support Systems | Material Well-being Education, Training and Employment Participation Environment | How well are Australia's children learning and developing? | Housing and the Environment Material Well-being Quality of School life |

Appendix

Datasets – Potential resources for the development of health and well-being indicators for children and youth with disabilities.

This appendix provides a very brief overview of national data sources, followed by a more detailed illustrative discussion of sources in one jurisdiction – Western Australia.

In Australia the main source of information regarding the number of people with a disability is from the 2003 Survey of Disability, Ageing and Carers (SDAC) conducted by the Australia Bureau of Statistics (ABS) (<http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features12003?OpenDocument>). The final sample for this survey comprised 36,241 people in general households and 5,145 people in supported accommodation.

- The National Aboriginal and Torres Strait Islander Social Survey 2008 (<http://abs.gov.au/AUSSTATS/abs@.nsf/mf/4714.0/>) includes information on disability in a sample of indigenous participants aged 15 years and over. A comparative analysis of disability rates is in [http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/F54883AEE4071013CA25706800757A2E/\\$File/47040_2005.pdf](http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/F54883AEE4071013CA25706800757A2E/$File/47040_2005.pdf)
- A disability question was included in the 2006 Australian Census (<http://www.abs.gov.au/websitedbs/D3310114.nsf/Home/Census>). This will enable small area data to be improved as well as supply information on sub-populations.
- The AIHW (<http://www.aihw.gov.au/disability/index.cfm>) is continuing to work on the implementation of the International Classification of Functioning, Disability and Health (ICF: <http://www.who.int/classifications/icf/en/>). The ICF has been developed to provide a framework for the conceptualisation, classification and measurement of disability. It recognises disability as a multidimensional and universal experience and will assist with future data collection and classifications for people with disabilities.

The national data collection on disability support services (<http://www.aihw.gov.au/publications/index.cfm/title/10751>) contains information about children receiving services, including a profile of their support needs across all the life domains represented in the ICF's Activities and Participation dimension – from learning, self care, mobility, to relationships and education.

- **'Growing Up in Australia' is the Longitudinal Study of Australian Children** (<http://www.aifs.gov.au/growingup/>) which

contains information on children with disabilities who are in the sample. The study, which is following the development of two cohorts of 5,000 children, aims to examine the impact of Australia's unique social and cultural environment on the next generation and will further understanding of early childhood development, inform social policy debate, and be used to identify opportunities for early intervention and prevention strategies in policy areas concerning children. 'Growing Up in Australia' explores family and social issues, and addresses a range of research questions about children's development and well-being. Its longitudinal structure will enable researchers to determine critical periods for the provision of services and welfare support and identify the long-term consequences of policy innovations.

- **Footprints in Time; is the Longitudinal Study of Indigenous Children**
(<http://www.fahcsia.gov.au/sa/indigenous/progserv/families/lisic/Pages/default.aspx>). This study aims to improve the understanding of, and policy response to, the diverse circumstances faced by Aboriginal and Torres Strait Islander children, their families and communities. Over 1,680 interviews were undertaken in Wave 1 with the parents and carers of two groups of children, mostly aged between 6 to 18 months and 3½ - 4½ years in Wave 1.
- **The Longitudinal Surveys of Australian Youth**
(<http://www.lsay.edu.au/>) The Longitudinal Surveys of Australian Youth (LSAY) track young people as they move from school into further study, work and other destinations. It uses large, nationally representative samples of young people to collect information about education and training, work, and social development. Survey participants enter the study when they turn 15 years, or as was the case in earlier studies, when they were in Year 9. Individuals are contacted once a year for 10 years. Studies began in 1995, 1998, 2003, and in 2006. Over 10,000 students start out in each cohort.
- **The Household, Income and Labour Dynamics in Australia (HILDA)** survey is a household-based panel study which began in 2001 (<http://www.melbourneinstitute.com/hilda/>). It collects information about economic and subjective well-being, labour market dynamics, family dynamics and some information on disability in a nationally representative sample of approximately 7,000 households each year.
- An overview of many of these and other sources was provided in the AIHW publication on 'Children with Disabilities in Australia' published by the AIHW in 2004 (<http://www.aihw.gov.au/publications/index.cfm/title/10086>), with an updated bulletin in 2006 (<http://www.aihw.gov.au/publications/aus/bulletin42/bulletin42.pdf>)

Western Australia Population Based Datasets

In Western Australia we have a number of datasets available to identify children with disabilities. These include:

Birth Defects Register

The Birth Defects Register collects information about babies born with birth defects diagnosed up to the age of 6 years. The registry defines a birth defect as 'a structural or functional abnormality that is present from conception or occurs before the end of pregnancy, and is diagnosed by six years of age' (Bower, Rudy, Callaghan, Cosgrove, & Quick, 2007). There are multiple sources of notifiers to the Birth Defects Register including doctors, parents and other child health professionals. Up to a maximum of 10 defects can be recorded for each child using the five-digit British Paediatric Association ICD-9 system. Also major and minor abnormalities are coded according to a method devised by the Centres for Disease Control in the United States. This information has been collected since 1980.

Cerebral Palsy Register

The Western Australian Cerebral Palsy register commenced in 1980 to monitor the occurrence of Cerebral Palsy in Western Australia and carry out research to investigate its causes and evaluate treatment strategies (Stanley & Watson, 1985). Cerebral Palsy is a chronic neurological condition affecting movement and posture, ranging in severity from barely noticeable to severely disabling. The dataset used contains information on children who were born in WA with cerebral palsy and also on children with cerebral palsy due to clearly documented post neonatal causes occurring before the age of 5 years (Watson, Blair, & Stanley, 2006). Therefore cases are defined as due to post-neonatal causes or pre and peri-natally acquired.

Intellectual Disability Exploring Answers (IDEA)

The IDEA database provides population based information on children diagnosed with intellectual disability in Western Australia based on medical and demographic data collected by the Disability Services Commission (Petterson, et al., 2005). These data have been enhanced by the addition of information provided by the Department of Education and Training on children registered with an intellectual disability in 1999, 2002 and 2004.

Autism Register

http://www.autismwa.org.au/autism_register.html

The WA Autism Register serves as a primary resource to researchers, clinicians and service providers to assist with our knowledge of this complex disorder. The WA Autism Register is prospective, collecting information on all people diagnosed in WA since January 1999. The Register collects information that is useful in describing the pattern of autism diagnoses in WA, including: the number and ages of people diagnosed, the severity of disability, shared biological, psychiatric and developmental features.

Department of Education - Schools Plus Dataset

The Education Department have a database called Schools Plus which contains information on public school students who fulfil the criteria for

requiring learning support and resources. There are eight eligibility areas including Physical Disability, Developmental Delay, Severe Medical, and Severe Mental Disorders (F20-F40).

Hospital Morbidity Database

The Hospital Morbidity Data collection is a database of information about all hospital admissions. The collection began in 1970 and includes summaries of all hospital admissions for patients admitted to public and private hospitals in Western Australia. The data includes demographic information, diagnostic and procedural information based on the International Classification of Disease (ICD) coding system (Western Australian Data Linkage Unit, 2006). There are 21 diagnostic codes and four external causes of admission codes (including assault and undetermined intent). The International Classification of Diseases and Related Health Problems is the international standard diagnostic classification developed by the World Health Organisation (WHO, 2004).

Measuring child well-being and potential factors impacting on children's well-being:

There are a number of areas where outcomes and well-being indicators could be measured at a population level in Western Australia. Some of these include:

- Education – literacy and numeracy attainment, school attendance and suspensions.
- Child Protection involvement – allegations of abuse and neglect, substantiated allegation, periods of care
- Health – number and frequency of hospital admissions, types of hospital admissions e.g. injury (intentional, accidental), infections, etc.
- Juvenile Justice contact – including juvenile justice team referrals, court orders, etc.
- Mental Health admissions – in patient public and private admissions, outpatient public admissions.
- Socioeconomic disadvantage – at birth, later disadvantage as obtained from postcodes recorded at hospital admissions.

The Developmental Pathways in Western Australia Project has linked the Health, Education, Child Protection and Juvenile Justice data and de-identified data is now available to look at outcomes for children who have been recognised in the data as having a disability. Outcomes for children with a disability can therefore be compared to the general population while taking into account factors such as age, gender, Aboriginality, socioeconomic disadvantage, etc.

Mental Health Data Collection

The Mental Health Information System collects data about people who use mental health services in Western Australia. It is a patient based information system in which each patient is allocated a unique number and demographic and clinical information is collected from public and private hospital in-patient admissions and public outpatient clinics. This information has been collected since 1966 (Department of Health, 2006).

Midwives Notification System

The Midwives Notification System collects information on all births in Western Australia (Gee, Hu, & Ernstzen, 2006). The registered midwife in attendance is required to provide information for all births, including live births or stillbirths of at least 20 weeks gestation or 400 grams birth weight. For multiple births a separate form is completed for each baby and all home births are recorded. The information collected includes maternal demographics, pregnancy conditions, labour and delivery outcomes and infant characteristics. This information has been collected since 1980.

Birth Registrations

The Birth Registration data is collected by the Department of the Attorney General (Department of Attorney General, 2009a). It is a legal requirement that every child is registered and requires both parents to complete and sign the birth registration form. The birth registration includes information relating to the parents' age, occupation and country of birth, marital status, date of marriage and the number of previous children. The information used in this dataset is from 1980 to 2005.

Death Registrations

The Death Registration data is collected by the Department of the Attorney General (Department of the Attorney General, 2009b). It is a legal requirement that a death is registered within 14 days of the date of death. Funeral Directors generally ensure that this requirement is met however the doctor who was responsible for the medical care of a person before their death or who examines the body after death must complete and sign a medical certificate of cause of death. The doctor is not required to give notice of the cause of death of a person in circumstances in which the death is reportable to the Coroner in which case the Coroner will make a determination on the cause of death. The death registration includes information relating to cause of death, age at death, and place of death. The Australian Bureau of Statistics codes the cause of death according to the International Classification of Disease coding system (Australian Bureau of Statistics, 2007). The information from the dataset was collected from 1980 to 2005.

Department for Child Protection

The Department for Child Protection (DCP), previously the Department for Community Development, has the main responsibility for the protection of children, aged up to 18 years, in Western Australia. DCP began its computerised child protection data system in 1989. From 1989 to 1993/94 DCP used a form based collection maintained on a personal computer (Family and Children's Services, 1996). However towards the end of 1993 all the data on the PC system was converted into the Client and Community Services System (CCSS). This resulted in staff moving from the form based data collection to be able to directly input client records into the CCSS.

The Child Protection data collection includes information on child protection allegations, substantiations and periods of out of home care from 1990-2005. Child protection allegations consist of reports made to the Department for Child Protection regarding allegations of child abuse or neglect, maltreatment

or harm to a child. An allegation is substantiated when, following investigation 'there is reasonable cause to believe the child has been, is being, or is likely to be abused or neglected or otherwise harmed' (AIHW, 2009). Out of home care could consist of kinship care in which children are placed with extended family, or a foster care placement in which children are placed with approved non-familial carers.

Juvenile Justice

The Juvenile Justice data contains information on juvenile justice contacts from 1990 onwards. Children can be charged for offences from 10 years of age and tried before the Children's Court for offences committed until the age of 18 years. This data includes information on juvenile justice charges, offences, court appearances and decisions made by the Children's Court, as well as juvenile justice team referrals and supervision orders.

Education

<http://www.det.wa.edu.au/education/walna/>

The Department of Education and Training from 1998 conducted a full cohort testing program called the Western Australian Literacy and Numeracy Assessment (WALNA) for Year 3, 5 and 7. In 2008 this was later expanded to test the outcomes for children in Year 9. As of 2009 the WALNA will be replaced by the National Assessment Program Literacy and Numeracy (NAPLAN). All students in Years 3, 5, 7 and 9 in schools across Australia undertake the same tests on the same days. Students have their skills assessed in Reading, Writing, Language Conventions (Spelling, Punctuation and Grammar), and Numeracy. All students are encouraged to participate in the national tests and special provisions are made to meet the needs of individual students with special needs.

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