

NDA

Identifying the care support needs of children
with disabilities

October 2012

Table of Contents

PURPOSE OF RESEARCH.....	4
METHODOLOGY.....	4
BACKGROUND.....	5
INTRODUCTION TO MEASURING CARE NEEDS	5
REVIEW OF THE DOMICILIARY CARE ALLOWANCE	7
CURRENT MEASURING OF CHILDREN’S CARE NEEDS.....	8
STANDARDS FOR ROBUST ASSESSMENT AND ASSESSMENT TOOLS AND ISSUES WITH ASSESSMENT.....	11
CRITERIA FOR STANDARDISED TOOLS	11
ISSUES WITH ASSESSMENT.....	14
<i>Rigour</i>	<i>14</i>
<i>The importance of process of assessment.....</i>	<i>15</i>
<i>Developing assessment tools.....</i>	<i>16</i>
<i>Factors to consider when using assessment instruments</i>	<i>17</i>
<i>Assessment tools for specific disabilities.....</i>	<i>18</i>
THE CARE NEEDS OF CHILDREN WITH DISABILITIES.....	21
CARE DEPENDENCY IN CHILDREN WITH DISABILITIES.....	21
DEFINING AND MEASURING CARE DEPENDENCY.....	24
STANDARDISED INSTRUMENTS FOR MEASURING CHILDREN’S SELF CARE: THE LITERATURE	26
STANDARDISED INSTRUMENTS THAT MEASURE FUNCTIONAL STATUS/CARE DEPENDENCE	30
<i>Functional Independence Measure (FIM) for older children and adults and the WeeFIM for younger children</i>	<i>30</i>
<i>The Paediatric Evaluation of Disability Index (PEDI) and the newer PEDI-CAT.....</i>	<i>33</i>
<i>The Vineland Adaptive Behaviour Scale (VABS) and the newer VABSII.....</i>	<i>36</i>
<i>SCIS.....</i>	<i>39</i>
<i>Comparison of the psychometric properties of Instruments WeeFIM, VABS, PEDI and SCIS.....</i>	<i>40</i>
<i>Care Dependency Scale for Paediatrics (CDS-P).....</i>	<i>41</i>
<i>Wisconsin Children’s Long-Term Supports Functional Screen (CLTS FS).....</i>	<i>44</i>
<i>The SIS for Children.....</i>	<i>47</i>
OTHER STANDARDISED INSTRUMENTS USED WITH CHILDREN (SCREENING/FUNCTIONAL STATUS)	48
<i>PEDS -Screening for development delay (Parents’ Evaluation of Developmental Status).....</i>	<i>48</i>
<i>The Ages and Stages Questionnaires (ASQ)-screening for developmental delay</i>	<i>49</i>
<i>Children with Special Health Care Needs (CSHCN) Screener.....</i>	<i>51</i>
<i>Questionnaire for Identifying Children with Chronic Conditions (QuICCC).....</i>	<i>55</i>
<i>Barthel Index of Activities of Daily Living (ADLs)</i>	<i>58</i>
INSTRUMENTS FOR AUTISM SPECTRUM DISORDER	60
<i>CHAT and M-CHAT.....</i>	<i>60</i>
<i>The Early Screener for Autistic Traits</i>	<i>60</i>
<i>The Social Communication Questionnaire (SCQ)</i>	<i>60</i>
<i>The Developmental Behaviour Checklist Early Screen.....</i>	<i>61</i>
<i>The Communication and Symbolic Behaviour Scale-Developmental Profile (CSBS-DP).....</i>	<i>61</i>
<i>The Pervasive Developmental Disorders Screening Test.....</i>	<i>61</i>
<i>The Screening Tool for Autism in Two Year Olds.....</i>	<i>61</i>

APPENDIX 1 TABLE OF SOME INSTRUMENTS MEASURING CARE NEEDS	62
<i>Wisconsin Children’s Long-Term Supports Functional Screen (CLTS FS)</i>	62
APPENDIX 2 DEFINING AND MEASURING CARE DEPENDENCY – NOT USING STANDARDISED INSTRUMENTS	63
DEFINING CARE DEPENDENCY: THE UK DOMICILIARY CARE ALLOWANCE	63
DEFINING CARE DEPENDENCY IN AUSTRALIA: THE DISABILITY CARE LOAD ASSESSMENT (CHILD) DETERMINATION (DCLA).....	64
APPENDIX 3 BURDEN OF CARE IN FAMILIES WITH A CHILD WITH A DISABILITY	66
APPENDIX 4 TABLES SHOWING DOMAINS OF VARIOUS INSTRUMENTS.....	70
THREE WIDELY USED STANDARDISED INSTRUMENTS FOR CHILDREN AND ADOLESCENTS TO ASSESS INDIVIDUAL FUNCTIONAL STATUS AND CARE DEPENDENCE	70
2. STANDARDISED INSTRUMENTS NOT WIDELY USED (AND NOT COPYRIGHTED).....	72
2.1. <i>Care Dependency Scale (CDS-P)</i>	72
2.2. <i>Wisconsin Children’s Long-Term Supports Functional Screen (CLTS FS)</i>	73
3. INSTRUMENT UNDER DEVELOPMENT: SIS-CHILD TO DETERMINE SUPPORT NEEDS.....	75
4. FUNCTIONAL STATUS II QUESTIONNAIRE (DOES NOT MEASURE CARE DEPENDENCE)	76
5. MEASURING SEVERITY AUTISM SPECTRUM DISORDER (AS OPPOSED TO AUTISM SCREENING TOOLS).....	77
6. TOOLS USED FOR AUTISM SCREENING.....	78
7. MULTIDIMENSIONAL CHILD AND ADOLESCENT GENERIC MEASURES OF HEALTH OUTCOMES ENCOMPASSING FUNCTIONAL, HEALTH STATUS AND HEALTH RELATED QUALITY OF LIFE FOR USE WITH GENERAL POPULATIONS OF CHILDREN AND ADOLESCENTS (DO NOT MEASURE DEPENDENCE PER SE).....	79
APPENDIX 5 PSYCHOMETRIC PROPERTIES OF WEEFIM AND OTHER INSTRUMENTS....	87

Purpose of research

The purpose of this research is

- To identify standardised assessment tools that might be useful in evaluating the care needs of children with disabilities across a range of age groups and disabilities within the context of entitlement to the Domiciliary Care Allowance.
- To briefly describe standardised tools for assessing care needs including their strengths and weaknesses
- To summarise and compare alternative instruments

Related to the above, it is relevant to consider

- Issues that should be explored before selecting a tool for measuring care needs
- Approaches internationally to identifying individuals and populations with additional care needs
- The broader context of developing a range of supports and services for all children with disabilities
- How the use of a standardised assessment tool might fit with other assessment processes

Methodology

Searches were carried out on standardised instruments for measuring care needs of children but also on carer's burden including economic burden and measuring various aspects of this burden.

Searches were carried out of the Social Sciences Citation Index, the Cochrane Collaboration, Pubmed Google and Google scholar using terms including:

children and disabilities and systematic reviews assessment tools; care dependency instruments; assessment tools; assessment tools activities of daily living; social assistance assessment instruments; eligibility assessment instruments; standardised instruments and hours of care needed; childhood disabilities; developmental screening tools; standardised instruments care needs; carers burden; measure caregiv*; carer burden; instruments measure hours care

Background

Introduction to measuring care needs

Children with care needs are a diverse group. The level of disability can vary from a mild speech difficulty to quadriplegia and so the level of dependency and the type and intensity of support and services required also varies. In addition to the diversity of disability, there can be varying needs for educational and social support as well as for personal care and home care. As well as child-specific factors, the need for support and services is influenced by environmental factors. Thus, the relationship between level of dependency and support and service needs are complex.

It is increasingly recognised that valid and reliable tools are needed to assess different kinds of disability and care needs and to guide service decisions: “There is a recognised need for more consistent and system-wide approaches to assessment for disability services, using tools that are widely accepted in the field. Determination of the level of service or funding that should follow on from assessment is a complex task, but it is a task that must be undertaken”¹.

¹ P.9 Submission to Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme From Anna L Howe, PhD, Consultant Gerontologist June,

Points to consider include

- Defining the purpose of the assessment will determine the type of assessment instruments required and the domains to be measured.
- Where the purpose is to determine which children with disability require care beyond the normal, the tool should comprehensively measure the care domain. This raises the question of how care and ‘care beyond the normal’ is best defined.
- In addition to assessment tools that can predict care needs, measures are needed that can demonstrate linkages between service and support provision for specific needs and child and family outcomes.
- A related issue is how instruments and assessment processes of care might dovetail with other statutory or non statutory assessment processes.
- There is growing interest in promoting self-care among adult populations and some evaluation of self-care support for children and young people with long term conditions has begun². It will be important to monitor, for example, how the establishment of a nation wide network of school based intervention teams for children with disabilities will impact on the needs of children with disabilities and if they will improve significantly outcomes for children with disabilities including their self-care abilities.
- It is relevant to define target populations and to highlight the difference between entitlement to and eligibility for services. Related to the latter it is important that clear policy decisions be taken around, for example, whether the best possible supports and services should be

2010. Accessed on 8th October at
www.pc.gov.au/__data/assets/pdf_file/0010/99487/sub0056.pdf

² Evaluating self-care support for children and young people with long-term conditions 2010 Report for the National Institute for Health Research Service Delivery and Organisation programme http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1715-162_V01.pdf

provided to a limited number of individuals or the best possible services and supports provided to everyone who needs them. For example, a waiting list of more than 3 months for children to be assessed or to receive therapy is generally considered unacceptable and, yet, with current resources, and a strong desire to do the very best for the children that get seen, there are currently waiting lists of up to 2 years or more in some parts of Ireland for children's services.

Review of the Domiciliary Care Allowance

A review of the Domiciliary Care Allowance (DCA) in Ireland is taking place. This is a scheme set up in 1973 by the Health Boards to provide financial assistance to parents of children with disabilities in recognition of their additional care needs.

The working review group of the DCA includes representatives from the Departments of Social Protection, Health, Children & Youth Affairs and Public Expenditure, as well as the National Disability Authority. It also includes three representatives from key NGO organisations representing parents/guardians of children who are in receipt of the allowance. It also includes other members with relevant expertise.

The review of the Domiciliary Care Allowance will examine the policy objectives and legal provisions underpinning the Scheme. In addition, it will review the Scheme's current administrative, medical assessment and appeals processes, including an examination of the duration of review periods for the Scheme. As part of its work, the Group will research best practice in other countries and will have the Medical Guidelines and the Report of the Expert Medical Group, which underpin the operation of the Scheme, reviewed by a suitably qualified medical expert. As part of the review, a consultation process with parents and representative groups will be undertaken to ensure that parents and their representatives have an opportunity to make their concerns known in relation to the administration of the Scheme.

Current measuring of children's care needs

Many countries providing financial assistance to parents of children with disabilities, in recognition of their additional care needs, do not use standardised instruments. Instead, most assessment processes use any information already available and evidence from health professionals. Agencies involved in approving financial assistance also often employ medical staff to review decisions made.

Berry and Smit (2011) compared the South Africa eligibility assessment tool with the UK Disability Living Allowance Tool (DLA) and the Australian Child Disability Assessment Tool (CDAT). In the South African study, the three instruments were used in a purposive sample of 18 children representing 6 different types of disability and chronic illness. The South African instrument deemed 56% of the sample ineligible while the majority were deemed eligible for assistance using the UK (94%) and Australian (89%) instruments³. None of these three instruments used to assess social assistance of children with chronic health conditions and disability are standardised.

Some countries are reviewing their payment systems. The UK is planning to replace the Disability Living Allowance (DLA) with a Personal Independence Payment and is developing a new "more objective" assessment of need. In Australia a 2007 taskforce on the Annual Child Disability Payment reported recommended "the development of a new suitable assessment tool⁴". A new assessment tool was introduced in

³ Berry, L., De V.Smit, A (2011) Social assistance needs of children with chronic health conditions: a comparative of international and South African Eligibility Assessment Instruments. *Social Work in Public Health*, 26; 635-650

⁴ Carer Payment (child): A New Approach Report of the Carer Payment (child) Review Taskforce. Accessed 8th Oct 2012 at <http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/publications-articles/carers-payment-child-a-new-approach-report-of-the-carer-payment-child-review-taskforce>

2009 and from 2010 a single assessment process was introduced for Carer Payment and Carer Allowance⁵.

Examples of payments, assessors and instruments in some English speaking countries are shown in Figure 1.

Figure 1 Examples of current payments, assessors and instruments

Country	Payment	Assessors and Instrument
Australia	Annual Child Disability Assistance Payment given for a child under 16 years who has a disability that attracts a Carer Allowance for their carer.	Assessment for Carer Allowance requires completion of questionnaires by the carer and by a health professional that can be a medical practitioner, registered nurse, occupational therapist, physiotherapist, psychologist, aboriginal health worker in geographically remote areas or a speech pathologist. In July 2010 the Disability Care Load Assessment (DCLA) was introduced.
New Zealand	Fortnightly Child Disability Allowance paid to the main carer of a child/young person with a serious physical, sensory, psychiatric or intellectual disability who requires constant care and attention. It is not income or means tested.	A Child Disability Allowance Application Form is used and the medical certificate in the application form needs to be completed by the doctor or specialist who provides the ongoing care of the child or young person. Between 2009 and 2011, the proportion of children aged under 18 years who were assisted by a Child Disability Allowance decreased slightly (from 4.2% to 3.6%). This decrease followed an increase between 2007 and 2009 (from 3.6% to 4.2%) ⁶ .
UK	Disability Living Allowance for a child with a severe physical or mental disability who have walking difficulties or who needs help in caring for themselves – the allowance contains a component for children who have	No formal instrument is used. The focus of the examination is on how a person's disability affects them. Assessments use existing information about a person's disability where possible. Where additional information is required a medical examination is conducted by a selected healthcare professional who has completed specialised training. Clients do not choose the

⁵ Improved Support for Carers: Changes to Carer Payment and Carer Allowance
http://www.fahcsia.gov.au/sites/default/files/documents/05_2012/carers_fact_sheet_7july10.pdf.

⁶ <http://statistical-report-2011.msd.govt.nz/supplementary+benefits/child+disability+allowance>

	significant caring needs – washing, dressing, help preparing meals, etc	examiner but can specify the preferred gender of examiner.
United States	Supplemental Security Income Benefits for Children under 18 with physical and mental conditions that seriously limit their activities.	The assessment for Supplemental Security Income includes a review of information that has been provided to support an application including medical information provided by a doctor. Staff may contact the child's doctor directly for further information or arrange additional examinations or tests to establish eligibility.
Ireland	Monthly Domiciliary Care Allowance given to the carer of a child with a disability under 16 years that requires care, attention and/or supervision in excess of what other child of the same age would require	Medical Assessment often completed by GP and reviewed by an Department Assessor
South Africa	Care Dependency Grant to the caregiver of children between 1 and 18 requiring permanent care due to severe physical or intellectual disability	Government employed medical practitioner must assess child to determine the severity of the disability, to verify that the child is in need of care and that the caregiver can adequately care for the child.

In the absence of any gold standard for determining additional or special care needs, a range of criteria are generally used. Most definitions of additional or special care needs use at least use one and usually more of the following four components:

- Functional limitations
- Presence of a health condition
- Need for health-related services
- Minimum expected duration of health condition of 12 months

Definitions differ in the specific criteria used to characterise each of the four components (functional limitations, presence of a health condition, need for health related services and duration of health condition) and how much emphasis is given to each. Definitions can also differ in their conceptual approach.

Medicaid (2002) proposed 5 key questions to identify children with special care needs⁷.

1. **Why do you want to identify children with special health care needs?** (to estimate prevalence, evaluate care, early identification)
2. **Who do you want to identify?** (Age group, enrolment status, unit of analysis – individuals versus cohort or population groups)
3. **How will you define special health care needs?**
 1. Functioning criteria – levels and types of functional limitations
 2. Presence of a condition – types of conditions, disease status and source of report
 3. Service–use need criteria – level, frequency and types of services
 4. Duration – length of time a condition must be present to qualify
 5. Conceptual approach: a) consequences–based approaches focusing on the manifestations of functional limitations or service needs that may be the result of chronic health conditions b) diagnosis based approaches which focus on the manifestations of functional limitations or service needs that may be the result of chronic health conditions and c) problem based approaches which use eligibility in specific programs.

Standards for robust assessment and assessment tools and issues with assessment
--

Criteria for standardised tools

There is no universally agreed tool for assessing the care and support needs of individuals. There is however, reasonable consensus about the

⁷ Approaches to Identifying Children and Adults with Special Health Care Needs 2002 A Resource Manual for State Medicaid Agencies and Managed Care Organizations Prepared by CAHMI The Child and Adolescent Health Measurement Initiative on behalf of the Centers for Medicare and Medicaid Services Accessed 10th October 2012 at <http://cahmi.org/ViewDocument.aspx?DocumentID=120>

attributes that any assessment tool must have. These include validity, reliability and rigour⁸.

A standardised tool should meet the following criterion:

- **Reliability:** A reliable measure is one that measures a construct consistently across time, individuals, and situations. A good measure should produce consistent results when the test is repeated within a reasonably short space of time (test–retest reliability) and when different assessors use the instrument to assess the same individual (inter–rater reliability).
- **Validity:** The key aspect of assessing validity is to pose the question: ‘What is the tool for?’ and ask whether it meets that purpose. For example, is an assessment tool intended to measure needs per se or needs that will be funded by the scheme. In order to be valid, a measure must be reliable, but the converse need not be true. Validity refers to the degree to which a measure accurately samples or assesses abilities or behaviours that reflects what is being tested. Criterion related validity of a screening test includes
 - **Sensitivity** – for example, the percentage of children with disability with care needs beyond the ordinary who are correctly identified by the screening test.
 - **Specificity** – the percentage of children with disability without care needs beyond the ordinary who are correctly identified by the screening test.
 - **Positive Predictive value** – the percentage of children with disabilities who are identified as having significant care needs and who do actually have significant care needs beyond the ordinary (true positives).

⁸ Disability Care and Support inquiry report released on 10 August 2011 Accessed 8th October at <http://www.pc.gov.au/projects/inquiry/disability-support/report>

- Negative Predictive value – the percentage of children with disabilities who are identified as not having significant care needs who actually do not have significant care needs (true negatives).
- Responsiveness is also important. This can be defined as the ability of an instrument to detect clinically important differences over time⁹.
- Appropriateness for use in a particular country
- Compatibility with agreed working definitions
- Direct and indirect costs to use
- Compatible with existing tools, forms and surveys
- Availability of tool and technical support

The Productivity Commission in Australia have proposed a National Disability Insurance Scheme (NDIS) to provide insurance cover for Australians in the event of significant disability or who have a disability with associated significant care and support needs¹⁰. The Commission wishes to develop a coherent ‘toolbox’ of assessment tools to be used across Australia to determine the level of needs and funding for a person covered by the scheme. Different tools would be suited to particular needs for support (for example, the need for aids and appliances compared with attendant care). Any tools used should be rigorous, valid (testing what they purport to), reliable (giving consistent results) and cost-effective¹¹.

⁹ Guyatt G, Walter S, Norman G. (1987) Measuring change over time: assessing the usefulness of evaluative instruments. *J Chronic Dis*, 40 (2) p171-8

¹⁰ Disability Care and Support: Inquiry report from the Productivity Commission – 10 August 2011 Accessed 18th October 2012 at http://www.pc.gov.au/__data/assets/pdf_file/0014/111272/disability-support-overview-booklet.pdf

¹¹ *ibid*

Issues with assessment

Rigour

“A dilemma for funding bodies in the context of individualised funding is that some individuals will overstate the extent of a disability in order to receive increased levels of funding. (This need not be by the person with disability. Under current arrangements, for example, service providers might face an incentive to overstate people’s needs to get more funding.) In some cases, people might be conscious of what others receive and may inflate their own claims¹².

An Australian study investigated whether assessment tools obtained different results for different purposes¹³. They found that the assessed support needs of individuals were much greater when they were assessed for funding purposes compared to when they were assessed for research purposes. There are a number of ways to reduce the risk of such ‘gaming’. These include the use of professional assessors, careful calibration and gatekeeping and the monitoring of data. But the choice of tools can also affect the scope for gaming with the use of objective and auditable measures reducing the risk of gaming¹⁴. It has been suggested that the use of objective functional measures are potentially less susceptible to manipulation and therefore may be more appropriately suited

¹² Disability Care and Support inquiry report released on 10 August 2011 Accessed 8th October at <http://www.pc.gov.au/projects/inquiry/disability-support/report>

¹³ Guscia, R., Harries, J., Kirby, N. and Nettelbeck, T. 2006b, ‘Rater bias and the measurement of support needs’, *Journal of Intellectual and Developmental Disability*, September, vol. 31, no. 3, pp. 156–60, Department of Psychology, University of Adelaide, cited in <http://www.pc.gov.au/projects/inquiry/disability-support/report>

¹⁴ Harries, J. 2008, *Support Needs Assessment for Individuals with Intellectual Disabilities: An investigation of the nature of the support needs construct and disability factors that impact on support needs*, PhD thesis, School of Psychology, University of Adelaide, September cited in <http://www.pc.gov.au/projects/inquiry/disability-support/report>

to funding purposes¹⁵. Where people receive an entitlement to supports rather than a budget to purchase those supports, the incentive to overstate needs is reduced. For example, a person would face little incentive to exaggerate their need for assistance in showering, if that only resulted in more showers (rather than a bigger budget)¹⁶.

The importance of process of assessment

The Australian Disability Care and Support Inquiry report (2011), considering an adult assessment process for individualised funding for support needs, suggested that the assessment process would:

- Assess the nature, frequency and intensity of an individual's support needs, regardless of how these might be met. While the process would be person-centred and forward looking, it would be focused on what was reasonable and necessary
- Consider what willingly and reasonably could be provided by informal carers. Informal carers who met a large share of a person's support needs would receive their own assessment if they wish
- Translate identified needs into a person's individualised package to be funded, after taking account of natural supports.
- The awarding body would periodically re-assess people's needs as their circumstances changed, especially at key transition points like leaving school, getting a job, moving out of home, or losing a natural support.
- A coherent package of tools (a 'toolbox') should be employed to determine the support needs and funding for a person covered by the

¹⁵ Dyson, M., Vile, S. and Allen, F. 2002, Review of Accommodation Support Funding Process, Disability Services Commission, Government of WA, Perth as reported in Guscia2006a and Harries 2008 cited in <http://www.pc.gov.au/projects/inquiry/disability-support/report>

¹⁶ Disability Care and Support inquiry report released on 10 August 2011 Accessed 8th October at <http://www.pc.gov.au/projects/inquiry/disability-support/report>

scheme. Different tools would be suited to particular needs for support (for example, the need for aids and appliances compared with attendant care). Any tools used should be rigorous, valid (testing what they purport to), reliable (giving consistent results) and cost-effective.

- Governments should not delay implementation of the scheme in the absence of ‘perfect’ tools but use the best available tools in its initial stages, with the later development of better tools.
- Excessively tough use of the assessment tool would be unfair, but ‘loose’ use would threaten scheme sustainability. To guard against both: assessments would be conducted by allied health professionals approved and trained in the use of the tools. They would be continually assessed for their appropriate use of the assessment tools
- The assessments would not be ‘rubber stamped’. Prior to making budgetary decisions, the awarding body would confirm that the particular assessment followed the appropriate protocol, and was consistent with a ‘benchmark’ range of assessed needs for other people with similar characteristics. Deviations outside the norm would require further investigation
- Any tools employed would be continually monitored and refined¹⁷.

Developing assessment tools

Systematic reviews of assessment tools for children and adolescents highlight that many instruments are developed but subsequently are not updated or used. Other instruments, while also demonstrating validity and reliability, are from unpublished dissertations and, again, are not widely used. “There seems to be a constant stream of new assessment tools when it would appear that the refinement and replication of previously developed assessments may be a more worthy use of time and

¹⁷ Disability Care and Support inquiry report released on 10 August 2011 Accessed 8th October at <http://www.pc.gov.au/projects/inquiry/disability-support/report>

resources”¹⁸. Crowe et al (2011) found 209 different social function assessment tools used in developing children aged 6–16 years. The majority of tools identified had less than 100 citations with about one third of the assessment tools identified having 10 or fewer citations, indicative of little usage outside the author’s own research¹⁹. Of the 2009 assessment tools found, 82 were excluded as they had been developed more than 20 years ago and not subsequently updated and 30 were excluded as they from unpublished dissertations²⁰.

Factors to consider when using assessment instruments

Colmar et al (2006) highlights that most adaptive functioning assessment tools fail to account for contextual factors that can impact on adaptive behaviour, such as socioeconomic status, mental illness in the family and time spent in appropriate educational facilities²¹. Failure to account for contextual and child-specific factors as influences on acquiring adaptive behaviours means there is no way of knowing why a child may not be displaying a particular skill. Therefore, when assessing the adaptive behaviour of a child, a consideration of the child’s present context and learning history needs to be included, such that present status is evaluated in relation to opportunity to learn²². In addition, limited

¹⁸ p.783 Crowe, LM., Beauchamp, MH., Catroppa, C., Anderson, V (2011) Social function Assessment tools for children and adolescents: a systematic review from 1988 to 2010 *Clinical Psychology Review* 31, p.767–785

¹⁹ *ibid*

²⁰ *ibid*

²¹ Hart, B., & Risley, T. (1999) *The social world of children learning to talk* Baltimore:

Brookes and Zigler, E. (1995). Can we “cure” mild mental retardation among children in the lower socioeconomic stratum? *American Journal of Public Health*, 85(3), 302–304 as cited by Colmar, S., Maxwell, A., Miller, L (2006) *Assessing Intellectual Disability in Children: Are IQ Measures Sufficient, or Even Necessary?* *Australian Journal of Guidance & Counselling*, 16 (2), 2006, p 177–188

²² Colmar, S. (2003, June). The importance of pausing and open questioning in facilitating opportunities to initiate and respond for children with language delays.

information is given from adaptive behaviour scales for intervention planning, although findings may provide an overview of what adaptive behaviours the child is displaying and the broad level of support needed to maintain skills and, ideally, to progress²³. Looking at the responses to individual items might facilitate program planning but other techniques such as the observation of adaptive behaviours, taking into account the specific antecedents and consequences of behaviours, and considering wider contextual factors may be required as well²⁴. In reporting findings, relevant cautions should be stated and, in general, the choice and mode of using adaptive behaviour measures should be considered so as to reduce the possibility of measurement error and to maximise the amount of reliable and valid information²⁵.

Assessment tools for specific disabilities

Intellectual disability

“Assessing children with intellectual disabilities requires using a combination of assessment tools to measure key aspects of a child’s

Australian Guidance and Counselling Association Newsletter, 3, p.12–18 as cited by Colmar, S., Maxwell, A., Miller, L (2006) Assessing Intellectual Disability in Children: Are IQ Measures Sufficient, or Even Necessary? Australian Journal of Guidance & Counselling, 16 (2), 2006, p 177–188

²³ Downing, J.E., & Perino, D.M. (1992). Functional versus standardized assessment procedures: Implications for educational programming. *Mental Retardation*, 30, 289–295 and Linehan, S.L., & Brady, M.P. (1995). Functional versus developmental assessment: Influences on instructional planning decisions. *Journal of Special Education*, 29, 295–309 as cited by Colmar, S et al (2006)

²⁴ Sattler, J.M. (2002). *Assessment of children: Cognitive applications* (4th ed. Vol. 1). San Diego, CA: Jerome M. Sattler as cited by Colmar, S et al (2006)

²⁵ Colmar, S., Maxwell, A., Miller, L (2006) Assessing Intellectual Disability in Children: Are IQ Measures Sufficient, or Even Necessary? Australian Journal of Guidance & Counselling, 16 (2), 2006, p 177–188 citing Leland, H. (1991). Adaptive behavior scales. In J.L. Matson & J.A. Mulick (Eds.), *Handbook of mental retardation* (pp. 211–221). New York: Pergamon Press.

cognitive functioning and adaptive skills, with a concomitant assessment of contextual influences. Adaptive behaviour scales are used to provide an overview of a child's demonstrated ability to function within society and their interpersonal competencies. Such tools may give an approximate idea of a child's strengths and special needs, although these tools are typically limited in their ability to provide practical and contextual information for planning and intervention purposes. It is crucial that the special characteristics of the child being assessed, and the limitations of the assessment instruments and methodologies used, are specified and noted in verbal feedback and written reports. If relevant recommendations are to be made and interventions are to facilitate progress, assessments need to be wide-ranging and to present a real picture of the child's strengths, as well as areas of special need. Ideally, a future-focused, dynamic assessment needs to be undertaken, taking into account changes that occur in the child's skills and capacity to learn over time. In addition, an evaluation should be made of how different contexts and interventions in the past might have impacted on the child's learning of and capacity to engage in specified behaviours²⁶."

Autism Spectrum Disorders

"Early detection and intervention can lead to substantially better prognosis. Early educational intervention optimizes long-term prognosis, including successful inclusion in regular education classroom. Interventions for children with ASD may show diminishing returns as the child gets older reinforcing the importance of starting intervention early. Since interventions do not usually begin before diagnosis, early screening and diagnosis are crucial. Guidelines by the American Academy of Paediatrics conclude that the positive effect of early diagnosis far outweighs the negative effects,

²⁶ Colmar, S., Maxwell, A., Miller, L (2006) Assessing Intellectual Disability in Children: Are IQ Measures Sufficient, or Even Necessary? Australian Journal of Guidance & Counselling, 16 (2), 2006, p 177-188

and families express the desire to be informed as early as possible”²⁷. “Questions concerning early autism screening are: (1) what screening age gives the best balance of accuracy against opportunities for early intervention; (2) can general developmental surveillance detect most cases of autism or are autism-specific screeners necessary; (3) are different questions needed to detect autism in young children in families from different cultures or language communities; (4) what is the most effective balance of clinician observation and parent report”²⁸. “However, the development of autism screening has advanced to the point where it should be routinely used in paediatric surveillance of development. The advantages so clearly outweigh the disadvantages that universal screening should be a recommended and an achievable goal. The current recommendation of the AAP, that is, ongoing general developmental surveillance from birth into school age, and autism specific screening at 18 and 24 months, is not yet supported by empirical data, but constitutes a cautious and reasonable approach that is likely to detect most cases of ASD and provide early referral for intervention. The availability of effective early intervention, of course, is a separate matter”²⁹.

Tools used for autism screening include CHAT, M-CHAT, the Early Screener for Autistic Traits, The Social Communication Questionnaire (SCQ), the Developmental Behaviour Checklist – Early Screen, the Communication and Symbolic Behaviour Scale – Developmental Profile (CSBS-DP), The Pervasive Developmental Disorders Screening Test, the Screening Tool for Autism in Two Year Olds³⁰.

²⁷ Barton, M., Chlebowski, C., Fein, D. Screening for Autism Spectrum Disorders in Young Children: A review of the literature. Accessed 18th October at <http://www.ncnp.go.jp/nimh/jidou/join/review.pdf>

²⁸ *ibid* – please see this review article for the many references on which it is based

²⁹ *ibid*

³⁰ *ibid*

The care needs of children with disabilities

Care dependency in children with disabilities

Children have differing abilities at different ages. Not being able to walk or get dressed alone is appropriate functioning for some age groups, but represents major disability in others. Relative to adults, the overall prevalence of childhood chronic disease is low, the number of potential conditions high, and few children experience any specific one. Consequently, when children are the targeted population, the definition of special health care needs selected must take these factors into account. That is why tools developed specifically for child populations are necessary³¹.

Tork (2007) in her doctoral thesis reviewed literature findings about the impact of a disability on children's care dependency³². While some authors argue that there is a difference between children with disabilities and those without disabilities in performing self-care, others argue that there is a difference only in the ability of children with certain types of disability in performing self-care and that cultural and other factors also

³¹ Approaches to Identifying Children and Adults with Special Health Care Needs 2002 A Resource Manual for State Medicaid Agencies and Managed Care Organizations Prepared by CAHMI The Child and Adolescent Health Measurement Initiative on behalf of the Centers for Medicare and Medicaid Services Accessed 10th October 2012 at <http://cahmi.org/ViewDocument.aspx?DocumentID=120>

³² Hanan Mohamed Mohamed Tork (2007) Care Dependency of Children in Germany and in Egypt—a Comparative Study Accessible at http://www.diss.fu-berlin.de/diss/servlets/MCRFileNodeServlet/FUDISS_derivate_000000003387/0_Care_dependency.pdf

influence ability to self-care³³. Msall and Tremont (1999) found that children with Down's syndrome were independent in changing positions, mobility, and bowel continence, and only a little supervision and assistance were required for bladder continence and dressing³⁴.

Care dependency among children with a disability may sometimes have a cultural background and/or be supported by the children's environment. For example, Francisco & Carlson (2002) reported that care independency in children in eating, drinking and dressing etc. was less valued in some cultures. Some parents viewed themselves as always being there for their disabled children and therefore performed many daily tasks for them³⁵.

Wong et al. (2002) showed that Chinese children of all ages in Hong Kong had better results in their self-care than their American counterparts. They stated that the differences might be attributable to the fact that Chinese children attended preschool settings, where they were taught to tend to their needs at an earlier stage than their American counterparts did³⁶. The presence of a maid at home was also found to impact on functional skills and, in general, girls mastered self-care and communication competencies before boys³⁷.

Similarly, Colmar et al (2006) point out that the context, including people, materials, activities etc, influences the adaptive behaviours that a

³³ ibid

³⁴ Msall ME, Tremont MR. Measuring functional status in children with genetic impairments. *Am. J. Med. Genet.* 1999; 89: 62-74, as cited by Tork (2007)

³⁵ Francisco I, Carlson G. (2002) Occupational therapy and people with intellectual disability from culturally diverse backgrounds *Australian Occupational therapy Journal* 49: 200- 211 as cited by Tork (2007)

³⁶ Wong V, Wong S, Chan K, Wong W. (2002) Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. *Pediatrics*; 109 (2) E36 Available at: <http://www.pediatrics.org/cgi/content/full/109/2/e36>.

³⁷ ibid

child might initially learn and subsequently express, particularly noting that the provision of opportunities to use a skill or to respond appropriately is critical³⁸. Many assessment instruments do not take into account contextual factors and, so, it may be unclear if the difficulty with adaptive skills is largely because of child-specific factors, such as a diagnosed genetic disorder like Down syndrome which is associated with limited cognitive abilities, or to environmental factors that have prevented the child from learning or having the opportunity to engage in appropriate adaptive behaviours.

While disability can have a direct effect on how care dependent children are, appropriate training and guidance can improve the ability of children with disabilities to take over the responsibility of their care³⁹.

According to Lewis and Iselin (2002) sighted children performed 84% of daily life activities without any assistance, while children with a visual impairment performed only 44% of those tasks independently⁴⁰. These differences might be related to the fact that visually impaired children are unable to watch how the tasks had to be performed; therefore, the

³⁸ Greenwood, C.R., Hart, B., Walker, D., & Risley, T. (1994). The opportunity to respond and academic performance revisited: A behavioral theory of developmental retardation and its prevention. In R. Gardner, D.M. Sainato, J.O. Cooper, T. Heron, W.L. Heward, J.W. Eshleman, & T.A. Grossi (Eds.), *Behaviour analysis in education* (pp. 213–223). Pacific Grove, CA:Brooks/ Cole as cited by Crowe, LM., Beauchamp, MH., Catroppa, C., Anderson, V (2011) Social function Assessment tools for children and adolescents: a systematic review from 1988 to 2010 *Clinical Psychology Review* 31, p.767–785

³⁹ Tork, HMM (2007) Care Dependency of Children in Germany and in Egypt—a Comparative Study Accessible at http://www.diss.fu-berlin.de/diss/servlets/MCRFileNodeServlet/FUDISS_derivate_000000003387/0_Care_dependency.pdf

⁴⁰ Lewis S, Iselin S. A comparison of the independent living skills of primary students with visual impairments and their sighted peers: a pilot study. *J. Visual Impair. Blin.* 2002; 96: 335 –344, as cited by Tork (2007)

acquisition of competence is delayed owing to the need for direct instruction and frequent opportunities to practise the tasks.

Defining and measuring care dependency

Children with disabilities may need extra care due to delayed development of self-care skills and/or a need for special care. Delayed self-care skills mean that care needs that are expected to diminish in typically developing children, persist⁴¹. Is care dependency about extra care required to perform daily living activities such as toileting, dressing or feeding a child with a disability or does it include, for example, the care involved in technology dependent children with high tech machinery at home?

Care dependency is usually measured by assessing functional status which is often conceptualized as the ability to perform self-care, self-maintenance and physical activities. The focus in functional assessment since its development is on the activities of daily living/basic care - Activities of Daily Living (ADLs) such as bathing and mobility. Lawton proposed the term instrumental activities of daily living (IADLs) to include other competencies needed by adults returning to the community⁴². IADLs encompass more complex activities needed to be self-reliant such as shopping, food preparation, money management, housekeeping, and use of transportation⁴³. Adaptive functioning or behaviour is a related though distinct concept. It is the ability to achieve expected age and cultural standards in personal independence and social responsibility and includes

⁴¹ Choo Henn Tean, S (2012) Assessment of activities of daily living in infants and children with developmental disabilities The Singapore Family Physician. 38(2) April - June 2012

⁴² Lawton MP (1971) The functional assessment of elderly people. J Am Geriatr Soc, 19, p. 456-81.

⁴³ Cohen, M., Marino, RJ (2000) The tools of disability outcomes research functional status measures Archive Phys Med Rehabil, 81 (2), s21-29

self care skills⁴⁴. Adaptive behaviour has been formally defined as a ‘collection of conceptual, social, and practical skills that have been learned by people in order to function in their everyday lives’. The specific areas in which the assessment of capacities is typically focused include: physical–motor, communication, self–care, home living, social, work, health and safety, self–direction, community use and leisure skills⁴⁵.

The International Classification of Functioning, Disability and Health (ICF), describe capacities as the individual’s ability to execute a task or an action, and are defined as the highest probable level of functioning that a person may reach in a given domain at a given moment in a ‘standardised or assumed’ environment. Limitations in the capacities of a child will lead to the need for additional care. This additional care has been defined as ‘dependency on medication or special diet, medical technology, assistive devices, personal assistance, need for medical care or related services or educational services over and above the usual for the child’s age, or for special ongoing treatments, interventions or accommodations at home or in school⁴⁶.

⁴⁴ Pierangelo, R., & Giuliani, G.A. (2002). *Assessment in special education: A practical approach*. Boston, MA: Allyn & Bacon and Venn, J.J. (2000) *Assessing students with special needs* (2nd ed.). Upper Saddle River, NJ: Prentice–Hall and Venn as cited by Colmar, S., Maxwell, A., Miller, L (2006) *Assessing Intellectual Disability in Children: Are IQ Measures Sufficient, or Even Necessary?* *Australian Journal of Guidance & Counselling*, 16 (2), 2006, p 177–188

⁴⁵ American Association for Mental Retardation. (2004). AAMR website <http://www.aamr.org> and Pierangelo, R., & Giuliani, G.A. (2002). *Assessment in special education: A practical approach*. Boston, MA: Allyn & Bacon as cited by Colmar, S., Maxwell, A., Miller, L (2006) *Assessing Intellectual Disability in Children: Are IQ Measures Sufficient, or Even Necessary?* *Australian Journal of Guidance & Counselling*, 16 (2), 2006, p 177–188

⁴⁶ Meester–Delver A, Beelen, A Hennekam R et al. *Predicting additional care in young children with neurodevelopmental disability: a systematic literature review*. *Developmental Medicine & Child Neurology* 2006; 48: 143–50. doi: 10.1017/S0012162206000314

Standardised Instruments for measuring children's self care: the literature

Tork (2007)⁴⁷ considers that the number of established standardised instruments to measure care dependency in children is limited and includes the WeeFIM, the Vineland Adaptive Behavior Scales (VABS), the Pediatric Evaluation of Disability Inventory (PEDI), the Self-Care Independence Scale and the Care Dependency Scale for Paediatrics (CDS-P) developed by her and colleagues for use in healthy children as well as for children with disabilities and derived from the adult CDS.

Choo Henn Tean (2012) considers that the choices for adaptive functional instruments include the WeeFIM (Functional Independence Measure), the Vineland Adaptive Behavior Scales (VABS), the Pediatric Evaluation of Disability Inventory (PEDI) and the Battelle Developmental Inventory (BDI)⁴⁸.

The PEDI, BDI and VABS are maximum data sets and involve detailed and extensive queries of self-care, mobility, communication and social items. On average, they require more than 30 minutes of interview time and complex scoring⁴⁹. The WeeFIM is useful in assessing functional independence in children aged 6 months to 7 years (up to 21 years in

⁴⁷ Tork, HMM (2007) Care Dependency of Children in Germany and in Egypt—a Comparative Study Accessible at

http://www.diss.fu-berlin.de/diss/servlets/MCRFileNodeServlet/FUDISS_derivate_000000003387/0_Care_dependency.pdf

⁴⁸ Choo Henn Tean, S (2012) Assessment of activities of daily living in infants and children with developmental disabilities The Singapore Family Physician. 38(2) April – June 2012

⁴⁹ Developmental Disabilities in Infancy and Childhood Vol I: Neurodevelopmental Diagnosis and Treatment. Chapter 21: Functional Assessment in Neurodevelopmental Disabilities and Msall ME. (2002) Tools for Measuring Daily Activities in Children: Promoting Independence and Developing a Language for Child Disability. Pediatrics, 109: 317–9. doi: 10.1111/j.1469-8749.2011.04133.x as cited by Choo Henn Tean (2012)

people with developmental disabilities) and can be administered by a trained interviewer in approximately 15 minutes⁵⁰.

Ottenbacher et al (1999) compared the performance on the Functional Independence Measure for Children (WeeFIM), the Battelle Developmental Inventory Screening Test (BDIST) derived from the BDI, and the Vineland Adaptive Behavior Scales (VABS) in children with developmental disabilities. The three instruments provide important information regarding childhood performance in motor, self-care, communicative, cognitive, and social skills. The WeeFIM instrument requires less administration time and provides information directly relevant to evaluating functional outcomes for children with disabilities and their families. There is a practical implication here in that the WeeFim instrument can be completed in approx 15 mins while the VABS takes approx 1 hour and the examiner is expected to be a graduate. The BDIST takes approx 30 mins (the BDIST is a modified version of the BDI which takes 2 hours to complete) but each item must be administered in a specific order which restricts its flexibility especially in use with young children⁵¹.

The WeeFIM is derived from the adult FIM and the Centers for Medicare and Medicaid Services (CMS) in the USA have chosen the FIM to calculate payment because there is a significant body of research on the reliability, validity, and responsiveness of the FIM. In adults when compared to the Barthel Index and Katz Index, the FIM scored highest in reliability, validity, and responsiveness, providing the best measure of

⁵⁰ Gurucharri L. (2003) Measuring Developmental and Functional Status in Children with Disabilities. *Pediatric Physical Therapy*; 15(1): 43-5. doi:10.1097/00001577-200301510-00009

⁵¹ Ottenbacher KJ, Msall ME, Lyon N, Duffy LC, Granger CV, Braun S. (1999) Measuring developmental and functional status in children with disabilities *Dev Med Child Neurol*; 41(3):186-94

disability⁵². The FIM has been found to be the most valid, reliable, and responsive global functional assessment tool that can be expressed as a summated rating scale because it exceeds the minimum psychometric properties⁵³. The purpose of the FIM has shifted over time. Before 2002 the FIM was used to determine personal and facility outcomes and predict resource needs. Since 2002 it has become the basis for reimbursement as well⁵⁴.

Choo Henn Tean (2012) highlights a screening questionnaire, the measurement of activities of daily living (M-ADL) that has been standardised and recently, validated in Germany. The M-ADL does not require trained interviewers, takes about 5 minutes to administer, and may serve as a tool for quick information on the level of activities according to the International Classification of Functioning, Disability and Health (ICF)⁵⁵. In the Netherlands, a Capacity Profile (CAP) has been developed to classify and measure additional care needs in children aged 3 to 18 years with permanent, non-progressive neuro-developmental disabilities. Preliminary evidence suggests that the need for additional care is relatively stable over time for this group of children and that CAP, if

⁵² Cohen, M. E., & Marino, R. J. (2000). The tools of disability outcomes research functional status measures. *Archives of Physical Medicine and Rehabilitation*, 81(2), S21-S29

⁵³ Stineman, M. G., Shea, J. A., Jette, A., Tassoni, C. J., Ottenbacher, K. J., Fiedler, R., et al. (1996). The Functional Independence Measure: Tests of scaling, assumptions, structure, and reliability across 20 diverse impairment categories. *Archives of Physical Medicine and Rehabilitation*, 77(11), p. 1101-1108.

⁵⁴ Cournan, M., (2011) Use of the Functional Independence Measure for Outcomes Measurement in Acute Inpatient Rehabilitation *Rehabilitation Nursing* 36 (3) p 111-117

⁵⁵ Blank R. (2007) Measurement of activities of daily living in children—standardisation of a screening questionnaire (abstract) *Klinische Padiatrie*; 219(1): 32-6. doi: 10.1055/s-2005-872494 and Blank R, Hengvoss S, Rollhausen E. (2009) Validation of a screening questionnaire for activities of daily living (M-ADL) in handicapped children (abstract). *Klinische Padiatrie*; 221(1): 31-7. doi: 10.1055/s-2007-984368

validated by prospective studies, may be used to classify the consequences of neuro-developmental disorders⁵⁶.

A 2004 study in Australia found that the PEDI has better psychometric properties than the WeeFIM and recommended it for measuring individual self care outcomes in children with acquired brain injury aged between 6 months and 7.5 years⁵⁷.

⁵⁶ Meester-Delver A, Beelen A, Hennekam R et al. (2007) The Capacity Profile: a method to classify additional care needs in children with neurodevelopmental disabilities. *Developmental Medicine & Child Neurology*; 49: 355-360. doi: 10.1111/j.1469-8749.2007.00355.x

⁵⁷ See <http://www.otcats.com/topics/CAT-Gall%20Galvin%20et%20al%202004%20WeeFim.pdf>

Standardised Instruments that measure functional status/care dependence

Functional Independence Measure (FIM) for older children and adults and the WeeFIM for younger children

The Functional Independence Measure (WeeFIM) for children is based on the conceptual framework of the Functional Independence Measure for adults⁵⁸. It is a similar tool to the adult FIM but differs in its scoring processes in order to take into account developmental stages.

The FIM can be used for children 8+ years

The WeeFIM can also be used in children aged between 8 and 12 years.

The WeeFIM is designed to assess the performance in self-care, mobility, and learning of children without disabilities between the ages of 6 months and 7 years and of children of all ages suffering from developmental disabilities and having a mental age of < 7 years⁵⁹.

⁵⁸ Azaula M, Msall ME, Buck G, Tremont MR, Wilczenski F, Rogers BT. Measuring functional status and family support in older school-age children with cerebral palsy: comparison of three instruments. Arch. Phys. Med. Rehabil. 2000; 81: 307–311 as cited by Tork, HMM (2007) Care Dependency of Children in Germany and in Egypt– a Comparative Study Accessible at

http://www.diss.fu-berlin.de/diss/servlets/MCRFileNodeServlet/FUDISS_derivate_000000003387/0_Care_dependency.pdf

⁵⁹ 21. Wong V, Wong S, Chan K, Wong W. Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics; 2002; 109 (2) E36 Available at: <http://www.pediatrics.org/cgi/content/full/109/2/e36> as cited by

If a child has had a FIM or WeeFIM assessment previously, wherever possible the same FIM instrument should be used.

The WeeFIM instrument includes 18 measurement items measuring

- Sphincter control: bladder management, bowel management.
- Locomotion: walk, wheelchair; stairs.
- Transfers: bed, chair, wheelchair, toilet, tub or shower.
- Communication: comprehension; expression.
- Social cognition: social interaction; problem solving, memory

The WeeFIM is a 7-level, criterion-specific ordinal scale. Level 7 requires no assistance for the child and the child completes the task independently without requiring a device. During the task, there is no concern about safety or taking an inordinate amount of time. Level 6 reflects modified independence and includes use of an assistive device or not completing the task in a timely or safe manner.

The advantages of the WeeFIM are its conciseness (simple scoring of 1–7), its comprehensiveness (covering all developmental aspects), a shorter administration time (it can be administered in 20 minutes or less) and the discipline-free requirements (can be administered by trained health, developmental or educational professionals)⁶⁰. The instrument is used in inpatient and outpatient paediatric settings for children.

A score of 1 through 7 is given for each of the 18 items. A score of 1 through 5 means that the child needs help to perform different daily task while score of 6 or 7 means that no help is required. WeeFIM

⁶⁰ Wong V, Wong S, Chan K, Wong W. (2002) Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. *Pediatrics*; 109 (2) E36
Available at: <http://www.pediatricsdigest.mobi/content/109/2/e36.full>

categorises into two functional streams: “Dependent” (i.e., requires helper; scores 1–5) and “Independent” (i.e., no helper; scores 6–7)⁶¹.

The WeeFIM has been tested in several studies and showed an excellent test–retest and interrater reliability and content validity⁶².

There is evidence that the instrument is responsive, that is, it can document changes in basic ADL functions over time in children with disabilities. “Future research on the responsiveness of the WeeFIM instrument and other paediatric disability rating scales should focus more on functional outcomes that are not only statistically significant but also important in the daily lives of children with disabilities and their families”⁶³.

The FIM has been used in several countries, including the US, Canada, France, Japan, Sweden and Germany and the FIM and Wee FIM are currently used by the NSW Lifetime Care and Support Authority in Australia⁶⁴. (Functional assessment using either FIM or the paediatric version WeeFIM® is part of the eligibility criteria for participation in the

⁶¹ Wong V, Wong S, Chan K, Wong W. (2002) Functional Independence Measure (WeeFIM) for Chinese Children: Hong Kong Cohort Pediatrics 109 (2) E36 Available at: <http://www.pediatricsdigest.mobi/content/109/2/e36.full>

⁶² Azaula M, Msall ME, Buck G, Tremont MR, Wilczenski F, Rogers BT. Measuring functional status and family support in older school-age children with cerebral palsy: comparison of three instruments. Arch. Phys. Med. Rehabil. 2000; 81: 307–311.

Palermo T, Childs G, Burgess E, Kaugars A, Comer D, Kelleher K. Functional limitations of school-aged children seen in primary care. Child Care Health Dev. 2002; 28: 379– 389

Wong V, Wong S, Chan K, Wong W. Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics; 2002; 109 (2) E36 Available at: <http://www.pediatrics.org/cgi/content/full/109/2/e36> [Accessed 15 October 2005].

⁶³ Ottenbacher, KJ, Msall, M., Lyon, N., et al (2000) The WeeFIM Instrument: Its Utility in Detecting Change in Children With Developmental Disabilities Arch Phys Med Rehabil; 81: 1317–26

⁶⁴ Assessment tools Productivity Commission Accessed 12th Oct 2012 at www.pc.gov.au

Lifetime Care and Support Scheme if the injured person has sustained a brain injury, multiple amputations or burns⁶⁵).

In Appendix 4 a table reproduces the results for the psychometric properties of the FIM and the other scales that scored highest in quality from 17 physical disability scales included in a chapter on scales for measuring physical disability and functioning in the 2006 Oxford University Press Edition of *Measuring Health: A Guide to rating scales and Questionnaires* by McDowell.

The Paediatric Evaluation of Disability Index (PEDI) and the newer PEDI-CAT

The PEDI is used to assess key functional capabilities and performance in children ages six months to seven years and to evaluate older children whose functional abilities are lower than those of seven-year-olds without disabilities. The PEDI measures both functional performance and capability in three domains

- self-care
- mobility
- social function

The Functional Skills section of the PEDI provides summary scores that reflect the child's current repertoire of daily life skills in each of the 3 domains (self-care, mobility, and social function), whereas the Caregiver Assistance section provides a summary of the extent to which the child's overall performance of complex daily tasks such as dressing or moving around is supported by help from a caregiver⁶⁶.

⁶⁵ New South Wales Government Lifetime Care & Support Authority Accessed 23rd Oct at http://www.lifetimecare.nsw.gov.au/fim_weefim.aspx

⁶⁶ Haley SM, Coster WI, Kao YC, Dumas HM, Fragala-Pinkham MA, Kramer JM, Ludlow LH, Moed R. (2010) *Pediatr Phys Ther*. Spring;22(1):69-75. Lessons from use of the Pediatric Evaluation of Disability Inventory: where do we go from here?

The most common application of the PEDI by therapists has been to document functional delay or changes in a child's functional abilities over time in response to therapeutic interventions⁶⁷. PEDI can detect functional gains in children⁶⁸. The PEDI was initially developed to assess children with cerebral palsy and is a valid assessment tool to investigate treatment effectiveness, particularly the effects of surgical and pharmacological interventions for children with cerebral palsy. The PEDI has been used to measure changes in functional abilities and caregiver assistance for groups of children admitted to hospital-based rehabilitation programs. Use of the PEDI has provided program managers with functional outcome data to provide feedback to staff and families about program performance. The PEDI has been shown to be responsive to changes in functional recovery in self-care, mobility and social function during rehabilitation hospital stays and at 6-month follow-up⁶⁹.

In one study the strengths were found to be that the scoring forms are easy to understand and assess, not all sections need be completed, the tool assesses both capability and performance and scores are standardized on a normative sample of children in the same age group. The weaknesses were identified as: can take a long time to complete, inter-responder reliability is not strong, setting and social expectations are not considered and rating scales are on an "all or none" basis⁷⁰

The combination of Functional Skills and Caregiver Assistance Scales in the same instrument has given researchers and clinicians a unique opportunity to investigate the relationship between acquisition of discrete skills and independence in management of larger daily tasks. A significant

⁶⁷ *ibid*

⁶⁸ Ketelaar M, Vermeer A, Hart H, van Petegem-van Beek E, Helders PJ. (2001) Effects of a functional therapy program on motor abilities of children with cerebral palsy. *Phys Ther.* Sep;81(9):1534-45.

⁶⁹ *ibid*

⁷⁰ *ibid*

gap between level of Functional Skills and level of Caregiver Assistance suggests that factors other than skill limitations may be affecting the performance of these tasks⁷¹.

Several authors have evaluated the reliability of PEDI, mostly in institutionalized children⁷². Validity has also been confirmed⁷³.

PEDI-CAT The PEDI research team has started a revision of the instrument including: (1) addition of items to extend the functional content assessed by the domains of self-care, mobility, and social functioning; (2) expansion of the dichotomous capable/unable scale to a 4-point difficulty scale; (3) addition of illustrations for each mobility and self care item; (4) replacement of the previous Caregiver Assistance section with a new "Responsibility" section; and (5) creation of a CAT platform for administration of content domains. Knowledge has been obtained about functional development from using the PEDI. In the PEDI-CAT, the innovations of the PEDI are retained but extended to include a more representative and larger sample of children across a wider age span. In the new PEDI-CAT, the CAT platform will be used with administration flexibility for clinical users and choices for score reporting. These advances are building on previous PEDI applications to make the assessment process more efficient and enhancing the value of

⁷¹ *ibid*

⁷² McCarthy, M.L., Silberstein, C.E., Atkins, E. A., Harryman, S.E., Sponseller, P.D., & Hadley-Miller, N.A. (2002) Comparing reliability and validity of pediatric instruments for measuring health and well-being of children with spastic cerebral palsy. *Developmental Medicine & Child Neurology*, 44, 468-476.

Nichols, D.S., & Case-Smith, J. (1996) Reliability and validity of the Pediatric Evaluation of Disability Inventory. *Pediatric Physical Therapy*, 8, 15-24.

Wright, F.V., & Boschen, K.A. (1993) The Pediatric Evaluation of Disability Inventory (PEDI): Validation of a new functional assessment outcome instrument. *Canadian Journal of Rehabilitation*, 7, 41-42.

⁷³ Feldman, A., Haley, S.M., Coryell, J. (1990) Concurrent and Construct Validity of the Pediatric Evaluation of Disability Inventory *Physical Therapy*, 70 (10), 602-610

the PEDI for clinical and research purposes for a broad age range of children both nationally and internationally⁷⁴.

The Vineland Adaptive Behaviour Scale (VABS) and the newer VABSII

The Vineland Adaptive Behaviour Scale (VABS) is used in children from birth to 18 years and ⁷⁵ measures

- Adaptive behaviour in children and adults
- Communication (receptive, expressive, written)
- Daily life skills (personal self-care)
- Socialization (interpersonal skills, playing, learning, and coping)
- Motor skills (gross and fine).

The focus of this test is the measurement of the adaptive behaviours, including the ability to cope with environmental changes, to learn new everyday skills and to demonstrate independence. The test measures five domains:

- The Communication Domain evaluates the receptive, expressive, and written communication skills of the child.
- The Daily Living Skills Domain measures personal behaviour as well as domestic and community interaction skills.
- The Socialization Domain covers play and leisure time, interpersonal relationships, and various coping skills.
- The Motor Skills Domain measures both gross and fine motor skills.
- Maladaptive Behaviour is an optional part of the assessment test. It is used when measuring obvious undesirable behaviours.

⁷⁴ Haley SM, Coster WI, Kao YC, Dumas HM, Fragala-Pinkham MA, Kramer JM, Ludlow LH, Moed R. (2010) *Pediatr Phys Ther*. Spring;22(1):69-75. Lessons from use of the Pediatric Evaluation of Disability Inventory: where do we go from here?

⁷⁵ Msall ME, Tremont MR. Measuring functional outcomes after prematurity: developmental impact of very low birth weight and extremely low birth weight status on childhood disability. *Ment. Retard. Dev. Disabil. Res. Rev.* 2002; 8: 258-272.

This instrument has also been proven to be an accurate resource for predicting autism and Asperger syndrome, among other differential diagnoses⁷⁶.

The VAB Scale has been nationally standardized in the USA using respondents who were stratified according to factors that could significantly influenced the answers to the items, such as gender, age, race, geographical region, size of community, and parental education. For the interpretation of scores, the procedure was developed by Angoff and Robertson, and is similar to that of the Kaufman Assessment Battery for Children, in which there are score equivalents for the raw scores in each domain, percentile ranks, age equivalents, adaptive levels, and maladaptive levels⁷⁷. In the USA the VABS may be purchased by members of the American Psychological Association, members of the National Association of School Psychologists (non-student members only), members of the American Speech-Language-Hearing Association (for speech, language, and auditory skills tests only), approved or accredited schools or colleges and government agencies, teachers with signed approval of an administrator (Level A and B tests only), graduate students with signed approval, and persons who are qualified at Level C⁷⁸.

VABS II Scales

The Vineland is designed to measure adaptive behaviour of individuals from birth to age 90. The Vineland-II contains 5 domains each with 2-3 sub-domains. The main domains are: Communication, Daily Living Skills, Socialization, Motor Skills, and Maladaptive Behaviour (optional). The

⁷⁶ <http://dpi.wi.gov/sspw/pdf/sswpginstrument.pdf>

⁷⁷ Accessible at <http://www.brighthubeducation.com/special-ed-law/13506-the-vineland-adaptive-behavior-scale/>

⁷⁸ Assessment Instruments Accessible at <http://dpi.wi.gov/sspw/pdf/sswpginstrument.pdf>

domain scores yield an adaptive behaviour composite⁷⁹. The Vineland-II is a standardized norm-referenced assessment tool. It can be used for:

- measuring an individual's daily functioning
- measuring deficits in adaptive behaviour
- clinical diagnosis of autism spectrum disorders, genetic disorders, developmental
- delays, emotional and behavioural disturbances as well as other mental, physical or injury related conditions
- developmental evaluations
- progress monitoring
- program planning
- research⁸⁰

The Vineland-II is designed to be administered individually. Eleven general sub-domains are grouped into four domains: communication, daily living skills, socialization, and motor skills. The domains are made up of sub-domains in which the scores are added to form the domain composite scores. The four domain composite scores then combine to form the adaptive behaviour composite for those individuals aged birth to 6 years 11 months. Three domain composite scores (communication, daily living skills and socialization) combine to form the adaptive behaviour composite for those aged 7 through 90. Using the interview format, the administration of the Vineland-II takes approximately 20-60 minutes. Using the parent/caregiver self report form requires between 30-60 minutes to complete⁸¹.

⁷⁹ Early Childhood Measurement and Evaluation Tool Review: Vineland Adaptive Behaviour Scales-Second Edition (Vineland-II) Accessible at http://www.cup.ualberta.ca/wp-content/uploads/2012/07/FINAL_Vineland_June-2012.pdf

⁸⁰ ibid

⁸¹ ibid

The Vineland-II Parent/Caregiver has been shown to be reliable and valid. Its rating form was standardized using a nationally representative American sample of 3,695 individuals from birth to 90 years. The norm sample was stratified according to demographic variables such as sex, race/ethnicity, socioeconomic status, and geographic region. The researchers also controlled for community size and special education program placement⁸².

“The Vineland-II is an instrument that requires graduate level training in psychology or social work and experience in assessment and test interpretation. This tool is targeted to institutions with personnel possessing masters and doctorates of psychology or social work, and has licensure in a relevant area of assessment with provincial or national organizations. The Vineland-II survey starter sets range from USD \$164.75 to USD \$398.35. Vineland-II scoring and reporting software ranges from USD \$290 to USD \$445.00 (May 2012)”⁸³.

SCIS

The Self-Care Independence Scale (SCIS) is a 44-item questionnaire that was developed for use in children with cystic fibrosis from 4-17 years. It is completed by parents. It is a disease-specific, self-care behaviour scale developed by a team of cystic fibrosis clinicians and researchers from Hahnemann University, Pennsylvania, USA⁸⁴.

⁸² *ibid*

⁸³ *ibid*

⁸⁴ Patton S, Graham J, Varlotta L, Holsclaw D. Measuring self-care independence in children with cystic fibrosis: the Self-Care Independence Scale (SCIS). *Pediatr. Pulmonol.* 2003; 36: 123-130.

Comparison of the psychometric properties of Instruments WeeFIM, VABS, PEDI and SCIS

Figure 2 The psychometric properties of WeeFIM, VABS, PEDI and SC⁸⁵

Purpose	WeeFIM	VABS	PEDI	SCIS
Author, yr	Multidisciplinary team health, educatn & Rehab professionals 1990 ⁸⁶	Sparrow et al.,1998 ⁸⁷	Haley et al. 1992 ⁸⁸	Team of Cystic Fibrosis clinicians & researchers1999
Domains	Self-care, mobility, communication, and social cognition	Daily life skills, motor, communication, & socialization	Self-care, social functional, motoric	Self-care, treatment
Application	Disabled and non-disabled Children	Disabled and non-disabled Children	Children with cerebral palsy	Children with cystic fibrosis
Target pop	Non-disabled: 6 mnths to 7 yrs Disabled: 6 mnths to 21 yrs	Children from birth - 18 yrs	Children from 6 months to 7.5 years	Children from 4-17 years
Method of Administration	Discipline-free requirements (can be admin by trained health, developmental or educational professionals)	Administered by the Child's caregiver	Administered by a Clinician	Administered by the parent

⁸⁵ This is taken from Tork, H (2007) Care Dependency of Children in Germany and in Egypt - a Comparative Study Thesis Submitted in Partial Fulfillment of The Doctoral Degree In Pediatric Nursing. Accessible at http://www.diss.fu-berlin.de/diss/servlets/MCRFileNodeServlet/FUDISS_derivate_000000003387/0_Care_dependency.pdf

⁸⁶ Azaula M, Msall ME, Buck G, Tremont MR, Wilczenski F, Rogers BT. Measuring functional status and family support in older school-age children with cerebral palsy: comparison of three instruments. Arch. Phys. Med. Rehabil. 2000; 81: 307-311.

⁸⁷ Sparrow S, Balla D, Cicchetti D. (1984) Vineland Adaptive Behavior Scale Interview Edition: Survey Form Manual. Circle Pines, MN: American Guidance Service.

⁸⁸ Haley SM, Coster WJ, Ludlow LH, Haltiwanger JT, Andrellos PJ. (1992) Pediatric Evaluation of Disability Inventory (PEDI). Version 1.0 Boston, MA: New England Medical Center Hospitals

Reliability	Excellent test-retest and interrater reliability, equivalence reliability	Excellent test-retest and interrater reliability	Excellent test retest and interrater reliability	Acceptable internal consistency, good testretest
Validity	Content validation by expert group, concurrent validity With VABS, AAQ	Excellent correlation with school-age IQ	Concurrent validity with Battelle and WeeFIM	Concurrent validity with a measure of patient selfcare Knowledge & HDQ
Admin time	15 min	45 min	45 mi	45 min

HDQ, Highland Dependency Questionnaire; PED1, Paediatric Evaluation of Disability Index; SCIS, Self-Care Independence Scale; VABS, Vineland Adaptive Behaviour Scale; WeeFIM, Functional Independence Measure.

Care Dependency Scale for Paediatrics (CDS-P)

This tool does not seem to be widely used. A paediatric version of the Care Dependency Scale (CDS-P) was developed from the Care Dependency Scale (CDS) for adults. The CDS for adults was developed in the Netherlands in 1996⁸⁹ for people with dementia and intellectual disabilities in psycho-geriatric nursing homes. It has a theoretical framework based on Henderson's (1966) human needs theory⁹⁰. The CDS items are, therefore, related to basic human needs independent from the cultural background. The CDS is easy to use and can be completed quickly, usually

⁸⁹ McCarthy, M.L., Silberstein, C.E., Atkins, E. A., Harryman, S.E., Sponseller, P.D., & Hadley-Miller, N.A. (2002) Comparing reliability and validity of pediatric instruments for measuring health and well-being of children with spastic cerebral palsy. *Developmental Medicine & Child Neurology*, 44, 468-476.

For example,

Ketelaar, Vermeer & Helders, 1988; Reid, Boschen & Wright, 1988; Wright & Boschen, 1993; Nichols & Case-Smith, 1996; McCarthy et al., 2002) This tool was developed by Dijkstra et al in 1996. See, for example, Dijkstra A, Brown L, Havens B, Romeren T, Zanotti R, Dassen T & Heuvel W (1999) An international psychometric testing of Care Dependency Scale. *Journal of Advanced Nursing* 31, 944-952 and Dijkstra A, Buist G, Moorer P & Dassen T (2000) A reliability and utility study of the care dependency scale. *Scandinavian Journal of Caring Science* 14, 155-161

⁹⁰ Henderson V (1966) *The nature of nursing: a definition and its implications for practice, research and education*. Macmillan Press, New York.

within less than five minutes⁹¹.The items comprising the CDS are shown in Figure 3. Each of the 15 items has an item description and five care dependency criteria.

Figure 3: The 15 human need items of the CDS

A Eating and drinking	I Avoidance of danger
B Continence	J Communications
C Body posture	K Contact with others
D Mobility	L Sense of rules and values
E Day/night pattern	M Daily activities
F Getting dressed and undressed	N Recreational activities
G Body temperature	O Learning activities
H Hygiene	

The CDS has been psychometrically tested in different European countries. In Germany it was tested as to its use in hospitals in different disciplines including the paediatric ward. It has been used in different age groups, health care settings (home care, community care, and institutional care) and populations (patients admitted on different wards in a hospital, nursing homes and accommodation for people with intellectual disability). The CDS is reliable in terms of internal consistency, equivalence and stability and psychometric properties regarding construct validity have been acceptable and showed similarities across countries.

Tork et al (2008) developed the CDS- P. They found that children with deafness, speech disorders, intellectual disability, and blindness significantly correlated with each other regarding the CDS-P items apart from 'continence' and 'play and hobbies'. This finding of theirs is similar

⁹¹ Dijkstra A, Coleman M, Tomas C, Va"lima"ki M & Dassen T (2003) Cross-cultural psychometric testing of the Care Dependency Scale with data. Journal of Advanced Nursing 43, 181-187

to that of Smith and Smith⁹² and Bruschini⁹³ who established that the acquisition of bowel and bladder control is almost the same in non-disabled children and those with mild disabilities and correlates with the level of mental disability. There was no significant difference between children in the different types of disability with regard to the area 'play and hobbies'. This could be explained by the fact that during playing children follow their abilities and not their disabilities. No child is ever taught how to play. Long before children use language to express their needs or to explain their actions they play; playing is a child's natural activity. The studies by Tork et al were done in school age children. Further studies are needed to test the applicability of the CDS-P to other age groups, such as pre-school age or adolescence and to assess the influence of the children's diagnoses on the CDS-P performance⁹⁴.

The paediatric version of the Care Dependency Scale (CDS-P) was developed from the adult CDS and its validity and reliability in Germany and in Egypt assessed⁹⁵. The CDS-P is a valid and reliable

⁹² Smith L & Smith P (1998) promoting continence training for people with learning difficulties Part One, *Journal of community Nursing* 12, 18-25

⁹³ Bruschini H, Faria N, Garcez E & Srougi M (2003) Development of bladder control in mentally handicapped children. *International Brazilian Journal of Urology* 29, 455-458

⁹⁴ CHAPTER 4 Care dependency of children in Egypt Tork H, Lohrmann C, & Dassen T. (2007) Accepted for publication in *Journal of Clinical Nursing* Accessed 12th Oct 2012 at http://www.diss.fu-berlin.de/diss/servlets/MCRFileNodeServlet/FUDISS_derivate_000000003387/0_Care_dependency.pdf?hosts=

⁹⁵ Tork, H., Dassen, T., Lohrmann, C (2008) Care dependency of children in Egypt, *Journal of Clinical Nursing*, p.287-295 and Tork, HMM (2007) Doctoral Dissertation on Care Dependency of Children in Germany and in Egypt—a Comparative Study Accessible at http://www.diss.fu-berlin.de/diss/servlets/MCRFileNodeServlet/FUDISS_derivate_000000003387/0_Care_dependency.pdf and Tork, H., Dassen, T., Lohrmann, C (2006) Care dependency of children in Egypt

measurement instrument offering a comprehensive assessment of care dependence⁹⁶. It has been recommended for assessing care dependency because of its psychometric properties and because it covers all aspects of care needs⁹⁷. Nurses rate all items by selecting one of the five criteria. The theoretical range of the CDS sum score is from 15–75. Low scores on the items indicate that patients are completely dependent on care. High scores mean that patients are almost independent of care⁹⁸. For an example of the modified scale, see Figure 4.

Figure 4 Example of an item of the modified Care Dependency Scale

Item	Eating and Drinking
Description Criteria	<p>The extent to which the child is able to satisfy his/her need for food and drink unaided</p> <p>(1) The child is unable to take food and drink unaided</p> <p>(2) The child is unable to prepare food and drink unaided; (e.g. He can not put the butter on the bread); child is able to put food and drink into his/her mouth unaided</p> <p>(3) The child is able to prepare and put food and drink into his/her mouth unaided; He has difficulties to determine the quantity ‘per spoon/per meals’.</p> <p>(4) The child is able to eat and drink unaided; He/she need some support</p> <p>(5) The child is able to prepare his/her meals and to satisfy his/her need for eating and drinking unaided.</p>

Wisconsin Children’s Long–Term Supports Functional Screen (CLTS FS)

The Wisconsin Children’s Long–Term Supports Functional Screen (CLTS FS) is a needs inventory and “functional assessment” to determine program eligibility and serves as a baseline for more in–depth assessment

⁹⁶ ibid

⁹⁷ Lohrmann C, Dijkstra A & Dassen T (2003a) The Care Dependency Scale: an assessment instrument for elderly patients in German hospital. *Geriatric Nursing* 24, 40–43.

⁹⁸ Dijkstra A, Coleman M, Tomas C, Va’lima’ki M & Dassen T (2003) Cross-cultural psychometric testing of the Care Dependency Scale with data. *Journal of Advanced Nursing* 43, 181–187.

to develop a service plan that reflects each child's and family's strengths, values, and preferences.

It was developed by the Department of Health and Family Services workgroup in 2002 – 2003, as part of Wisconsin's Children's Long-Term Support Redesign project. It built upon the success of Wisconsin's Long-Term Care Functional Screen (LTC FS) for adults, which since 1999 has been providing on-line eligibility determinations and specific levels of care for Wisconsin adults with long-term needs (frail elders and people with physical and developmental disabilities). The LTC FS has proven to be accurate and reliable⁹⁹.

The CLTS FS is completed by certified screeners through an interview with the child and parent(s), usually in the home. It has been programmed into an electronic application that yields virtually instant eligibility results for multiple Medicaid and state- and county-funded programs for children with long-term supports needs.

The CLTS FS is complex because:

- It must work well for children from birth through young adult (age 22 years) with a variety of functional abilities, health-related needs, and disability types (physical, intellectual, or emotional disabilities, and/or mental illness)
- It determines eligibility for multiple programs having different eligibility criteria
- It determines specific nursing home levels of care
- Specific diagnoses are required for eligibility for some programs.

Details of the instrument can be accessed online¹⁰⁰.

⁹⁹ For more information, see <http://dhfs.wisconsin.gov/LTCare/FunctionalScreen>

¹⁰⁰ Wisconsin Children's Long-Term Supports Functional Screen

The components of the CLTS FS are as follows:

- Activities of Daily Living (ADLs) including age appropriate skills in bathing, dressing, grooming, mobility, transfers, eating, and toileting
- Instrumental Activities of Daily Living (IADLs) including, as appropriate for the child's age, communication, learning, meal preparation, and money management
- Behavioural Needs
- Mental Health and Psychiatric Symptoms
- Diagnoses
- Demographics, including information about county of residence and responsibility, living situation and medical insurance
- Work and School including information about the current school/work situation as well as supports needed and interests for future employment
- Health-Related Services including skilled nursing tasks, therapies, and other medically-oriented interventions

The CLTS FS has been shown to be accurate, objective and reliable with good “inter-rater reliability”. It can be used for children of all ages with emotional, cognitive and physical disabilities, or developmental disabilities and with or without skilled nursing needs and in any setting from homeless to hospitals or institutions. CLTS FS Development and Validity Testing have been ongoing since 2001. The CLTS FS has been shown to have

- Content validity
- Criterion validity
- Predictive and construct validity
- Sensitivity

<http://www.dhs.wisconsin.gov/lcure/functionalscreen/cltsfs/cltsfsvalidity.pdf>

- Specificity
- Discriminant evidence
- Reliability (the consistency and ability of the instrument to produce similar results under similar circumstances)

In summary Wisconsin's CLTS FS is a generally reliable eligibility tool that yields consistent results for long-term support program eligibilities, level of care, and type of disability, when administered in similar circumstances within the same time frame by workers who receive appropriate training. While there is documented efficacy of the Wisconsin CLTS FS, the instrument is a dynamic and evolving tool.

Strengths It is free and there are downloadable pdf and forms available online with instructions

Weaknesses Reliable when used by certified screeners/professionals and time to administer varies depending on complexity of individual being screened

The SIS for Children

The Supports Intensity Scale (SIS) for Children provides a standardized procedure and a reliable and valid means to measure the relative intensity of support needs of children with intellectual disabilities and related developmental disabilities. An intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. These limitations create a mismatch between what a child is able to do and what the environment requires (for a child of a similar age and from a similar culture), which results in needing types and patterns of support that most other children do not need¹⁰¹.

¹⁰¹ Supports Intensity Scale for Children Field Test Version 1.1 American Association on Intellectual and Developmental Disabilities July 6, 2009 James R. Thompson – Illinois State University Michael Wehmeyer – University of Kansas Susan R. Copeland –

Adaptive behavior (AB) scales measure aspects of conceptual, practical, and social intelligence. Completing AB scales involve making judgments about whether a person does or does not typically perform specific observable skills and tasks. In contrast, the SIS-Children requires judgments to be made about the frequency, duration, and type of supports that a child needs to successfully participate in a wide range of life activities. Therefore, when completing the SIS-Children the focus is not on what specific, skills or tasks the child is able to do, but rather on what types of support the child needs to receive in order to fully participate in a variety of activities.

Other Standardised Instruments used with children (Screening/functional status)

PEDS – Screening for development delay (Parents’ Evaluation of Developmental Status)

This consists of 2 open-ended questions and 8 yes/no questions. It is written at a fifth-grade reading level and takes approximately 5 minutes to administer if an interview is needed—and even less time if parents can complete it independently. It need not be administered by a professional, and can be completed by a parent while waiting to see the doctor or even at home before a well-child visit. Parents can complete PEDS in the waiting room or at home before a visit

PEDS was published in 1997 as a developmental screen entirely dependent on one kind of parental report—their concerns. The instrument was standardized and validated with 771 children representative of the

University of New Mexico Carolyn Hughes – Vanderbilt University Todd D. Little – University of Kansas Shea Obremski – University of Kansas James R. Patton – University of Texas Ed Polloway – Lynchburg College Rodney E. Realon – North Carolina Mental Health, Developmental Disabilities and Substance Abuse Services Robert Schalock – Schalock Consultants Debbie Shelden – Illinois State University Marc J. Tassé – University of South Florida

1996 US Census¹⁰². Twenty-five percent of the children used in standardization lived in poverty, 30% had unmarried parents. This questionnaire has a sensitivity of 74% to 79% and a specificity of 70% to 80% across ages 0 to 8 years in the detection of developmental delays and behavioural problems. It maintains its psychometric properties across various levels of parental education, socioeconomic status, and child-rearing experience¹⁰³. The sensitivity and specificity for all ages combined was 75% and 74%, respectively.

Validity was determined through comparison with a battery of tests including the Woodcock-Johnson Psychoeducational Battery: Tests of Achievement, Stanford-Binet Intelligence Scale, and the Bayley Scales of Infant Development-II. Scoring stratifies risk as low, medium, and high. Children at high risk require referral for more comprehensive assessment; validity studies found approximately 70% to possess disabilities or substantial delays on further evaluation. Children at intermediate risk require further screening, as approximately 30% were found to have disabilities or substantial delays on in validation studies.

The Ages and Stages Questionnaires (ASQ)-screening for developmental delay

The Age and Stages Questionnaire (ASQ) system (formerly known as the Infant Monitoring Questionnaires) was developed by Bricker, Squires, and colleagues at the University of Oregon. It is a low-cost and easily administered screening instrument relying on parental report. Items are written at a fourth- to sixth-grade reading level; illustrations and examples are often provided. This self-administered assessment can be completed in 10 to 20 minutes and scored in 1 to 5 minutes. Parents can complete Ages and Stages in the waiting room or at home before a visit

¹⁰² Glascoe FP, Byrne KE. The accuracy of three developmental screening tests. *J Early Interv* 1993;17:368-378.

¹⁰³ Glascoe FP. *Parents' Evaluation of Developmental Status*. Nashville, Tenn: Ellsworth and Vandermeer Press; 1997.

The writers of the ASQ drew on several standardized developmental tests for item statements as well as literature that outlined early developmental milestones. They selected skills that could be observed or elicited easily by parents at home in the course of daily activities.

Early intervention for learning disabilities and language delays is generally thought to improve outcomes

The system has 19 questionnaires designed to be administered at ages 4 months through 5 years, corresponding to common well-child visits. Five developmental areas are covered in each questionnaire—communication, gross motor, fine motor, problem solving, and personal-social. Five items query skills in each area. An overall section has 5 questions that cover general parental concerns.

Normative data were gathered from 2008 children drawn from an ethnically and socioeconomically heterogeneous population, with 81% of children judged “at-risk¹⁰⁴.” The items were picked to represent the developmental quotient (DQ) of 75 to 100. Validity data were gathered from the analysis of 247 children, a subset of the population used in gathering normative data.

The ASQ has a specificity ranging from 81% (16 months) to 92% (36 months), and 86% overall. There was trend toward higher specificity when screening older children. Sensitivity was lower, averaging 72%¹⁰⁵. Age-appropriate tests of individual cognition were used as the gold standard, including the Bayley Scales of Infant Development, Stanford-Binet Intelligence Test (4th ed), and the McCarthy Scales of Children’s Abilities.

¹⁰⁴ Bricker D, Squires J. Low cost system using parents to monitor the development of at-risk infants. *J Early Intervent* 1989;13:50-60.

¹⁰⁵ Squires J, Bricker D, Potter L. Revision of a parent-completed developmental screening tool: ages and stages questionnaires. *J Ped Psychol* 1997;22:313-328.

The instrument maintains its validity when screening high-risk children: when specifically used to evaluate infants born prematurely, the ASQ had 90% sensitivity, 77% specificity¹⁰⁶. In this study formal assessment was performed with the Griffith Mental development Scales, Bayley Development Intelligence Scale.

Children with Special Health Care Needs (CSHCN) Screener

The Children with Special Health Care Needs (CSHCN) Screener was designed as an efficient way to identify children with ongoing physical, mental, behavioural or other conditions who also require a type or amount of health and related services beyond that required by children generally¹⁰⁷. Since 2000, it has been consistently used in three national surveys and numerous international population-based surveys as well as in health care quality measurement surveys, numerous studies and for other applications. Its validity properties have been routinely analyzed, reviewed and documented¹⁰⁸.

CSHCN Screener asks about the need or use of four health and related services (prescription medications; above routine medical, mental or educational services; specialized therapies; mental health treatment/counseling) and a fifth item about functional limitations in doing things similar aged children can do. This functional limitation item was included to provide some level of stratification by functional impact. Of the approximately 22% of children meeting this criteria, nearly 99% also met at least one of other service need or use criteria¹⁰⁹.

¹⁰⁶ Skellern CY, Rogers Y, O'Callaghan MJ. A parent-completed developmental questionnaire: follow-up of ex-premature Infants. *J Ped Child Heal* 2001;37:125-129.

¹⁰⁷ Bethell, C., Blumberg, S., Newacheck, P., Stein, R. Taking Stock of the CSHCN Screener: Key Design Features & Application Issues Accessed 4th Oct 2012 at <http://hdwg.org/sites/default/files/CSHCNScreenerPoster.pdf>

¹⁰⁸ *ibid*

¹⁰⁹ *ibid*

The cornerstone of the CSHCN Screener is to identify a health consequence prior to asking whether the consequence is due to an ongoing condition. Using this consequences-based approach it is expected that children with chronic health problems that result in elevated service needs will be identified, even if a specific diagnosis is not yet known. This is an especially important feature in cases where there is a large gap in time between symptoms, consequences and diagnosis. Additionally, having consequences at the first tier of screening allows for control over misdiagnosis or children whose conditions are so mild as to not require special health care services¹¹⁰.

The CSHCN Screener is a five item, parent survey-based tool that responds to the need for an efficient and flexible standardized method for identifying CSHCN. It provides a comprehensive and flexible method for identifying CSHCN. It requires minimal time to administer and is acceptable for use as both an interview-based and self-administered survey¹¹¹.

The CSHCN Screener was initially designed and tested by The Child and Adolescent Health Measurement Initiative (CAHMI) for use in the NCQA HEDIS endorsed Consumer Assessment of Health Plans Survey—Children with Chronic Conditions in 1999. It was subsequently incorporated into the 2001 NS-CSHCN and has since been used in the 2005/06 NS-CSHCN and the 2003 and 2007 National Survey of Children's Health. Since 2000, the CSHCN Screener has been consistently used in the Medical Expenditures Panel Survey (MEPS) and in numerous studies and published articles. The survey takes approximately 1 minute to administer.

¹¹⁰ *ibid*

¹¹¹The CSHCN Screener Accessed 3rd Oct 2012 at <http://depts.washington.edu/dbpeds/Screening%20Tools/CSHCN-CAMHIScreener.pdf>

It is available in self and interviewer administered formats, in Spanish and adolescent completed and adult versions exist¹¹².

The CSHCN Screener uses non-condition specific, consequences based criteria to identify children with special health care needs for purposes of quality assessment or other population-based applications. Children are identified on the basis of experiencing one or more current functional limitations or service use needs that are the direct result of an on-going physical, emotional, behavioural, developmental or other health condition.

The CSHCN Screener was developed through the efforts of the Child and Adolescent Health Measurement Initiative (CAHMI), a national collaboration coordinated by FACCT—The Foundation for Accountability. Beginning in June 1998, the CAHMI brought together federal and state policymakers, health care providers, researchers and consumer organizations into a task force for the purpose of specifying a method to identify children with special health care needs. The CSHCN Screener was developed using the federal Maternal and Child Health Bureau (MCHB) definition of CSHCN¹¹³ and building on the conceptual and empirical properties of the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) and other consequence-based models for identifying CSHCN¹¹⁴.

Common Questions about the CSHCN

Under-Identification: At-risk children were excluded from the CSHCN Screener. Additionally, some children with functional difficulties are not

¹¹² *ibid*

¹¹³ “Children who have special health care needs are those who have...a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

¹¹⁴ The CSHCN Screener Accessed 3rd Oct 2012 at <http://depts.washington.edu/dbpeds/Screening%20Tools/CSHCN-CAMHIScreener.pdf>

identified by the CSHCN Screener. Overall, 15.3% of children do not report functional difficulties and 11.6% of children have 1+ reported conditions but no functional difficulties. Of children with 1+ reported conditions and no functional difficulties, 91.5% stated that this was because their health problems are being treated and are under control. This could be due to child's interventions, due to normal development, or perceptual differences by parents. Parents may perceive that their child is functioning in an optimal way for their condition and some may misinterpret the "compared to similar-age children" as "compared to similar-age children with the same condition".

Over-Identification. Some have questioned whether the presence of a prescription medication need or use should constitute a special health care need. It is important to recognize that to qualify on this item, the medication need or use must be a consequence of a medical, behavioural or other health condition that has lasted or is expected to last at least 12 months, excluding prescription medications that are only for acute conditions. Moreover, while 44% of CSHCN in the 2005/06 NS-CSHCN qualified on the prescription medication item alone, children in this group had nearly twice as many doctor visits, are almost three times as likely to have two or more emergency room visits and four times as many functional difficulties compared with children without special health care needs on functional items included in the survey. Additionally, there is concern over whether children with asthma and allergies should be considered CSHCN. Of note, only 49% of children reported to have asthma and only 16% of children reported to have allergies also qualify as CSHCN. While children with asthma or allergies only have less needs and functional difficulties than other CSHCN, they are still different from Non-CSHCN regarding number of doctor visits, functional difficulties, and multiple emergency room visits¹¹⁵

¹¹⁵ Bethell, C., Blumberg, S., Newacheck, P., Stein, R. Taking Stock of the CSHCN Screener: Key Design Features & Application Issues Accessed 4th Oct 2012 at <http://hdwg.org/sites/default/files/CSHCNScreenerPoster.pdf>

Findings demonstrate that responses to the CSHCN Screener have good internal psychometric properties and include minimal random measurement error. Epidemiologists, clinicians and others can rely on CSHCN Screener responses to reliably identify CSHCN experiencing 1 or more of the 5 consequences included on the CSHCN Screener¹¹⁶.

Questionnaire for Identifying Children with Chronic Conditions (QuICCC)¹¹⁷

The QuICCC was specifically designed to operationalize the conceptual definition of children with chronic conditions and disability developed through the National Child Health Assessment Planning Project (NCHAPP) that was funded by the federal Maternal and Child Health Bureau (MCHB). The definition focuses on health-related consequences present as the result of having a childhood chronic condition, rather than diagnostic labels and etiology.

The Questionnaire for Identifying Children with Chronic Conditions (QuICCC) is an interviewer-administered instrument for identifying children with a chronic or disabling condition. It consists of 39 question sequences administered either by telephone or in-person interview to the parents or guardians of children under age 18.

The Household Version of the QuICCC collects data for all children in a family. It takes seven to eight minutes on average to screen all children in a household. The Household Version does not provide person-level results. If a detailed profile for each child is desired, then the Individual Version of the QuICCC must be used.

¹¹⁶ Carle, Blumberg....Internal psychometric properties of the Children with Special Health Care Needs Screener Acad Pediatr. 2011 Mar-Apr;11(2):128-35. Epub 2010 Mar 15.

¹¹⁷ Approaches to Identifying Children and Adults with Special Health Care Needs 2002 A Resource Manual for State Medicaid Agencies and Managed Care Organizations Prepared by CAHMI The Child and Adolescent Health Measurement Initiative on behalf of the Centers for Medicare and Medicaid Services Accessed 10th October 2012 at <http://cahmi.org/ViewDocument.aspx?DocumentID=120>

A brief form of the QulCCC was developed. The Questionnaire for Identifying Children with Chronic Conditions–Revised (QulCCC–R) is a 16–item subset of the original 39 QulCCC items. In testing, the QulCCC–R demonstrated greater than 98 percent agreement with the longer QulCCC instrument¹¹⁸. The Individual Version of the QulCCC–R takes less than two minutes to administer per child.

A set of three definitional elements described by Stein et al. are used to determine the presence of a chronic health condition or disability: 1) the disorder is biological, psychological, or cognitive in origin; 2) the expected or actual duration is as least 12 months; and 3) the disorder produces some type of functioning, service use, or dependency consequence¹¹⁹.

The QulCCC uses consequences–based criteria to identify children with chronic health conditions or disability. The following must all be present to qualify:

- The child currently experiences a specific consequence
- The consequence is due to a medical, behavioural, or other health condition
- The duration or expected duration of the condition is 12 months or longer

The QulCCC measures consequences in three domains:

1. Functional limitations (16 questions);

¹¹⁸ Stein REK, Silver EJ, Bauman LJ. Shortening the questionnaire for identifying children with chronic conditions: what are the consequences? *Pediatrics*. 2001;107(4):e61.

¹¹⁹ Stein RE, Bauman LJ, Westbrook LI, Coupey SM, Irely HT. Framework for identifying children who have chronic conditions: the case for a new definition. *J Pediatrics*. 1993;122:342–347.

2. Dependence on compensatory mechanisms and assistance (12 questions)

3. Above routine service use for age (11 questions)

The first part of each question asks about a specific consequence. If the respondent reports that a child experiences the consequence, the interviewer moves to the second part of the question, which asks whether it is the result of a medical, behavioural, or other health condition. If the response is “yes,” the interviewer then proceeds to the final part of the question, which asks if the duration or expected duration of the condition is one year or more. To classify as having a chronic health condition or disability, a child must have a “yes” response to all parts of at least one question sequence.

The final version of the QuI CCC instrument was field-tested in a national study (712 households, representing 1,388 children) and an inner city population (657 households, representing 1,275 children)¹²⁰. In these studies, results from the QuI CCC were compared to parents’ descriptions of their children’s health conditions, a checklist of childhood health conditions from the National Health Interview Survey (NHIS), and functional status scores on the Functional Status-II(R) Measure. Compared to the NHIS diagnostic checklist, the QuI CCC identified a wider range of disorders. Use of the checklist alone would have resulted in missing about one-quarter of the children identified by the QuI CCC because the specific conditions named by their parents were not included on the list. On the other hand, the QuI CCC excluded those children identified by the checklist who were not currently experiencing significant health-related consequences, who had single or recurrent episodes of acute conditions, and who had past conditions that resolved. These

¹²⁰ Stein REK, Westbrook LE, Bauman LJ. Questionnaire for identifying children with chronic conditions (QuI CCC): a measure based on a noncategorical approach. *Pediatrics*. 1997;99:513-521.

findings helped confirm the validity of the consequences based approach used by the QulCCC.

The QulCCC and the QulCCC-R are available in English or Spanish. Self-administered versions are not currently available.

The QulCCC is available at no cost; however, it is a copyrighted instrument and may not be reproduced without written permission from its developers.

The QulCCC was originally developed for epidemiological purposes such as prevalence estimation¹²¹. Later, it was validated as a screening tool for individual child identification¹²².

Barthel Index of Activities of Daily Living (ADLs)

The Barthel Index of Activities of Daily Living (ADLs) was developed in 1965¹²³ and later modified by Granger et al¹²⁴. It measures functional disability by quantifying patient performance in 10 activities of daily life. These activities can be grouped according to self-care (feeding, grooming, bathing, dressing, bowel and bladder care, and toilet use) and mobility (ambulation, transfers, and stair climbing).

5-point increments are used in scoring, with a maximal score of 100 indicating that a patient is fully independent in physical functioning, and a lowest score of 0 representing a totally dependent bed-ridden state. A

¹²¹ *ibid*

¹²² Stein REK, Bauman LJ, Epstein SG, Gardner JD, Walker DK. How well does the questionnaire for identifying children with chronic conditions identify individual children who have chronic conditions? *Arch Pediatr Adolesc Med.* 2000;154(5):447-452.

¹²³ Mahoney FI, Barthel DW. Functional Evaluation: The Barthel Index. *Md State Med J* 1965;14:61-65.

¹²⁴ Granger CV, Dewis LS, Peters NC, et al. Stroke rehabilitation: analysis of repeated Barthel index measures. *Arch Phys Med Rehabil* 1979;60:14-17.

five-item short form of the Barthel Index is also available¹²⁵. The test takes approximately 5 minutes to complete and should be used as a record of what a patient does, not of what a patient can do. Direct testing of the patient is not needed, as information can be derived from friends/relatives and nurses; although, the best available evidence should be used in evaluating the patient's performance. Originally designed by Mahoney and Barthel for use in scoring improvement during rehabilitation of patients with chronic neuromuscular or musculoskeletal disorders, the Barthel index has also been validated in the setting of primary brain tumors and brain metastases and is considered easy to use, reliable and sensitive to change¹²⁶.

Psychometric properties: The Barthel Index has been reported to have good reliability and validity and adequate responsiveness to change, in measuring neurologic physical disability. Hobart et al. compared psychometric properties of the Barthel Index with newer and lengthier scales, the Functional Independence Measure (FIM) and the Functional Independence Measure + Functional Assessment Measure (FIM+FAM), in patients undergoing rehabilitation. All three rating scales demonstrated equivalent reliability and validity in measuring physical disability, and were similarly responsive to change. This study suggested that the rating scales of FIM and FIM+FAM offered few advantages over the more practical and economical Barthel Index. Similar results were observed in studies of patients with multiple sclerosis and stroke¹²⁷.

¹²⁵ Hobart JC, Thompson AJ. The five item Barthel index. J Neurol Neurosurg Psychiatry 2001;71:225-230.

¹²⁶ See references in Summary Article Title of measure: Barthel Index of Activities of Daily Living (ADLs) Accessible at <http://www.rtog.org/LinkClick.aspx?fileticket=WFmhDMpabFE%3D&tabid=118> This summary was last revised 3 December 2010.

¹²⁷ See references in summary article Title of measure: Barthel Index of Activities of Daily Living (ADLs) Accessible at <http://www.rtog.org/LinkClick.aspx?fileticket=WFmhDMpabFE%3D&tabid=118> This summary was last revised 3 December 2010.

Currently, there are no fees for use of the academic not-for-profit use of the Barthel Index. A fee may be charged if a pharmaceutical company is sponsoring the trial. Website or how to register to use: Go to www.copyright.com to get permission to use the Barthel Index, copyrighted to the Maryland State Medical Society. Search under “Maryland State Medical Journal,” the journal in which the index was initially published¹²⁸. Through this website, a request for academic license can be made. A representative from the Maryland State Medical Society should respond to you within a few days. If no response is received, consider contacting the Society directly at www.medchi.org. The permission information should be given to RTOG headquarters for each RTOG QOL study. List any fees for usage:

Instruments for Autism Spectrum Disorder

CHAT and M-CHAT

The CHAT was adapted for use in the United States. The adapted tool retained the original 9 parent report items, eliminated the home visitor observation, and added fourteen parent report items, mostly related to early social-communication and joint attention. The Modified Checklist for Autism in Toddlers (M-CHAT) is a 23 item (yes/no) parent report checklist designed to identify signs of ASD in children aged 16–30 months.

The Early Screener for Autistic Traits

The Early Screener for Autistic Traits (ESAT) is a level one screener designed for use with 14–15 month old children.

The Social Communication Questionnaire (SCQ)

The Social Communication Questionnaire (SCQ), is a 40 item parent report measure, originally designed for use with children aged four and older based on the Autism Diagnostic Interview.

¹²⁸ Mahoney FI, Barthel DW. Functional Evaluation: The Barthel Index. Md State Med J 1965;14:61–65.

The Developmental Behaviour Checklist Early Screen

The Developmental Behaviour Checklist Early Screen is a 17-item parent report measure, which consists of items empirically selected to differentiate children with autism and developmental delay from children without autism. Items were selected originally from the Developmental Behaviour Checklist, a broad measure of emotional and behavioural problems in children with intellectual delays.

The Communication and Symbolic Behaviour Scale-Developmental Profile (CSBS-DP)

The Communication and Symbolic Behavior Scale – Developmental Profile (CSBS-DP) is a three part system designed to identify communication delays in children between the ages of 6 months and two years. It includes a 24-item parent questionnaire, the Infant-Toddler Checklist, which serves as a level one screen, although this tool is not specific to ASD. Children who screen positive on this measure are administered a more detailed Caregiver Questionnaire and an observational assessment of social communicative behaviours and interactive and symbolic play.

The Pervasive Developmental Disorders Screening Test

The Pervasive Developmental Disorders Screening Test II (PDDST-II) is a multi-stage screening tool. Stage 1 of the measure includes 22 items descriptive of typical behaviour in 12-24 month old children and is designed for use as a level 1 screen in primary care settings.

The Screening Tool for Autism in Two Year Olds

The Screening Tool for Autism in Two Year Olds (STAT) was designed as a level 2 screen to distinguish children with ASD from children with other developmental concerns. It includes twelve behaviours to be rated from observation of children in a structured play-based interaction and permits classification of children into high risk and low risk categories. A recent evaluation of the measure included several samples of children with Autistic Disorder, Pervasive Developmental Disorder and Developmental Delay or Language Impairment. The results suggest that the STAT has very strong test-retest and inter-rater reliability for the high and low risk classification.

Appendix 1 Table of some instruments measuring care needs

Instrument and cost	Purpose	Age	Measures
<p>WeeFIM and FIM</p> <p>Annual licensure allows access to the FIM™ instrument; its data collection software application, the FIMware® software; training and credentialing; and U.S. benchmarks.</p> <p>Couldn't find cost</p>	<p>The WeeFIM can be administered by direct observation, interview or a combination of both</p> <p>Tests motor and cognitive skills</p> <p>Self-care, mobility, and learning</p>	<p>WeeFIM children with and without disabilities 3 to 7 years and all children with a mental age < 7 years.</p> <p>FIM children 8+</p>	<p>MOTOR</p> <p>Sphincter control: bladder management, bowel management.</p> <p>Locomotion: walk, wheelchair; stairs.</p> <p>Transfers: bed, chair, wheelchair, toilet, tub or shower.</p> <p>COGNITION</p> <p>Communication: comprehension; expression.</p> <p>Social cognition: social interaction; problem solving, memory</p>
<p>Wisconsin Children's Long-Term Supports Functional Screen (CLTS FS) downloadable pdf forms available online with instructions.</p> <p>Free</p>	<p>Interview with child and parent Needs inventory & "functional assessment" to determine program eligibility</p>	<p>0-22 years</p>	<p>ADLs, IADLs, Behavioural Needs, Mental health, Diagnoses, Demographics, Work, School, Health Related Services</p>
<p>The Vineland Adaptive Behaviour Scale (VABS) and the VABS for infants and toddlers called the Vineland SEEC Scales specifically for children of ages zero to 5 years and 11 months</p> <p>VABSII improved scale and there is a classroom edition</p>	<p>Administered to parent or caregiver</p> <p>Assesses social abilities</p>	<p>VABS 3-18yrs</p> <p>Vineland SEEC Scales for children ages zero to 5 years and 11 months</p>	<p>Adaptive behaviour in children and adults</p> <p>Communication (receptive, expressive, written)</p> <p>Daily life skills (personal self-care)</p> <p>Socialization (interpersonal skills, playing, learning, and coping)</p> <p>Motor skills (gross and fine)</p> <p>Vineland Seec Scales Interpersonal Relationships, Play and Leisure Time and Coping Skills</p>

Costly			
PEDI Manual \$125.95 dollars and 25 PEDI Scoring Forms \$45.60	Functional skills and caregiver assistance skills	6 mnths – 7 yrs and older children whose functional abilities are lower than those of 7yr olds without disabilities	self-care mobility social function

Appendix 2 Defining and Measuring Care Dependency - not using standardised instruments

Defining care dependency: the UK Domiciliary Care Allowance

The UK Decision Maker's Guide for allowances updated in June 2012¹²⁹ specifies that before awarding a domiciliary care allowance, the assessor must look at the evidence and consider

- Whether there is a disability
- What bodily functions are impaired: functional status

¹²⁹ The Decision Maker's Guide UK Attendance allowance and Disability Living Allowance Vol 10 Amendment 34 June 2012 Accessed 19th Oct 2012
<http://www.dwp.gov.uk/publications/specialist-guides/decision-makers-guide/>

- Whether the person reasonably requires attention in connection with those functions
- How often the attention is required and how long it takes

Attention with bodily functions in the Guide is defined as some personal service of an active nature in connection with bodily functions, including

- Breathing
- Dressing
- Drinking
- Eating
- Eliminating waste products
- Getting in or out of bed
- Hearing
- Sitting
- Sleeping
- Walking
- Undressing
- Functions of the brain

There are other criteria to be applied as well.

Defining Care Dependency in Australia: the Disability Care Load Assessment (Child) Determination (DCLA)

In Australia to be eligible for a carer payment for a child one must be providing “constant care” for a child with a severe disability. However, there is no definition of “constant care” in Social Security law. Centrelink guidelines say that you are providing constant care if you personally

provide care on a daily basis for a “significant period” each day. The care you provide may be active, supervisory or monitoring¹³⁰.

The DCLA is a legislative instrument in Australia which replaced the former Child Disability Assessment Tool and is used to decide about carer payment and carer allowance in respect of a child with a disability under 16 years. It contains 2 questionnaires, one completed by the carer (ACL questionnaire) and another completed by the treating health professional (THP questionnaire) about the child's functional ability, behaviour and special care needs¹³¹. Based on the DCLA assessment of the functional ability, behaviour and special care needs of a child, a rating is determined. To be given a qualifying rating under the DCLA to receive allowances under the SSAct for the care of a child aged under 16 years it is necessary to receive a qualifying score on the ACL and a qualifying score from the Professional questionnaire¹³². The scoring methodology is specifically designed to take into account that, for children, there is some requirement for assistance with certain activities of daily living as the child moves through well recognised and accepted developmental milestones. Accordingly, the assessment focuses on what is required above and beyond regular requirements in these functional domains, as well as special care needs and their intensity¹³³. The ACL Questionnaire is separated into four domains: A – Behaviour; B – Behaviour; C – Functional Abilities and D – Special Care Needs. Domain A consists of eight questions on behaviour: everyday tasks; sleeping;

¹³⁰ Carer Payment and Carer Allowance for people caring for children updated January 2012. Accessed 18th October 2012 www.welfarerights.org.au/Factsheets/fscpca_child.doc,

¹³¹ Accessed at http://guidesacts.fahcsia.gov.au/guides_acts/ssg/ssguide-3/ssguide-3.6/ssguide-3.6.12.html on 2nd October 2012

¹³² *ibid*

¹³³ Senate Community Affairs Committee ANSWERS TO INQUIRY INTO SOCIAL SECURITY LEGISLATION AMENDMENT (IMPROVED SUPPORT FOR CARERS) BILL 2009 QUESTIONS ON NOTICE and ADDITIONAL INFORMATION Provided on behalf of the Department of Families, Housing, Community Services and Indigenous Affairs April 2009 Accessed 18th October 2012 www.aph.gov.au/Parliamentary.../Senate_Committees

irritable behaviour; speaking and listening and interaction with other children. Each of these questions has four possible responses which are essentially: always, often, sometimes and never¹³⁴. Claimants have reported difficulty in providing an understanding of, for example, how often a child displays irritable behaviour. Claimants consider that this is a difficult question/task for a parent to answer¹³⁵.

Appendix 3 Burden of care in families with a child with a disability

To decide how best to support care-givers in their role, governments and policy makers need comprehensive information on the care needs of children with disabilities and also on the costs of the financial, emotional and clinical burden borne by parents. Parents and other informal caregivers experience economic burden and health and wellbeing effects. The shift in emphasis to community care is set to place an increased care-giving responsibility on families. Governments recognise the benefits that accrue to the health and social care sectors from the informal care that families and other caregivers provide to children with severe disabilities and resource allocation decisions try to account for the “invisible-hands”-effects of carers¹³⁶. But how is this best done? The care needs of children and the burden on the family both need to be assessed.

¹³⁴ <http://espressedlife.wordpress.com/2012/07/24/putting-the-cart-before-the-horse-how-administrative-procedural-forms-identify-reality/>

¹³⁵ *ibid*

¹³⁶ Van Exel J, Bobinac A, Koopmanschap M, Brouwer W (2008) The invisible hands made visible: recognizing the value of informal care in healthcare decision-making. *Expert Review Pharmacoeconomics Outcomes Res*, 8(6), p.557-61 as cited in Hodek et al., (2011) Measuring economic consequences of preterm birth – Methodological recommendations for the evaluation of personal burden on children and their caregivers. *Health Economics Review*, 1:6 Accessed on 17th Oct 2012 at <http://www.healtheconomicreview.com/content/1/1/6>

A 2007 review of research published between 1989 to 2005 on the economic burden incurred by families as a result of caring for a child with disabilities was carried out¹³⁷. The review showed that little research has been performed to accurately reflect the costs incurred on families as caregivers for children with disabilities. Annual direct consumption costs associated with severe physical childhood disabilities such as cerebral palsy and spina bifida showed a range from \$108 to \$8,742.16 (the upper estimate was reported in a study of just sixteen families). The variability in reported costs is probably due to a lack of standardisation in the methodological approaches taken e.g. studies did not measure the severity of disability nor provide information on how disabilities were categorised or how severity was determined.

Dobson et al (1998) in the UK estimated that \$6036 annually was the sum of additional costs for a severely disabled child compared with a healthy child¹³⁸.

Stabile and Allin (2012) examined the literature on economic costs of childhood disability and concluded that the theoretical and empirical literature suggests substantial costs, direct and indirect, of having a child with a disability. Again, they found that estimates of cost vary depending on the methodology, jurisdiction, and data used. The costs estimated included contemporary costs (family earnings, stability, expenditures and program spending) and lifelong costs (human capital cost and earnings for the disabled child). Their estimates of economic costs varied between \$20,000 and \$60,000 with an average of \$30,500 annually per family with a child with a disability¹³⁹.

¹³⁷ Anderson et al (2007) The Personal Costs of Caring for a Child with a Disability: A Review of the Literature. *Public Health Rep.* 122(1): 3–16

¹³⁸ Dobson, B., Middleton, S., (1998) Paying to Care: The Cost of Childhood Disability (York, U.K.: YPS Joseph Rowntree Foundation.

¹³⁹ Stabile, M., Allin, S. (2012) The Economic Costs of Childhood Disability *The Future of Children* 22 (1) p. 65–96 Accessed 17th Oct 2012
http://www.princeton.edu/futureofchildren/publications/docs/22_01_04.pdf

Croen et al (2006) looked at the costs of medical services for children with and without autism spectrum disorders in a large group-model health plan. Annual utilisation and cost of health services per child was calculated. The study found that the utilisation and costs of health care are substantially higher for children with autism spectrum disorders compared with children without autism spectrum disorders.¹⁴⁰

Hodek et al (2011)¹⁴¹ outlines domains that could be used to measure economic burden of preterm birth on the main caregiver (usually parents) and these domains could also be applied to the economic burden of any disability/ill-health on the caregiver and include:

- Medical direct costs – outpatient e.g. visits to doctors, therapists, medication, aids and devices, outpatient visits, home care and inpatient e.g. hospitalisation,
- Non-medical direct costs e.g. transport, accommodation, meals, special education/schooling, home help
- Indirect Cost e.g. income losses, missed working days, time losses (opportunity costs)
- Intangible costs in terms of quality of life (QoL) of parents or other caregivers and QoL of children – Impact on Family Scale measures the impact that a child's illness/disability has on family function¹⁴².

¹⁴⁰ Croen et al (2006) A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics*, 118(4), e1203-1211

¹⁴¹ Hodek et al (2011) Measuring economic consequences of preterm birth – Methodological recommendations for the evaluation of personal burden on children and their caregivers *Health Economics Rev*,1:6 Accessed 17th Oct 2012 at www.healtheconomicsreview.com/content/1/1/6

¹⁴² Stein, REK., Riessman, C.K., (1980) The development of an impact on family scale: preliminary findings. *Med Care*,18, 465-72 as cited by Hodek et al (2011)

Family Adaptability and Cohesion Evaluation Scale II (Faces II) evaluates parental perceptions of family adaptability and cohesion¹⁴³.

A 2003 literature search (1966–2002) and review of self-report instruments to measure the burden, needs and quality of life of informal caregivers identified 28 instruments¹⁴⁴. The study evaluated the tools in terms of content, development and psychometric properties. While the tools were developed to measure burden, needs or quality of life, there was overlap in the dimensions of the caregiver experience they measure. It may be that there could be a synthesis between the various lines of research to more exactly define and measure the care giving experience and to assess variation in that experience as interventions and time proceed. As the questionnaires underwent statistical testing, the domains identified are likely to be the essential ones to make an assessment of the care giving experience. The study showed that there tools available for use by clinicians, researchers and others but future research is needed to use these instruments to assess the effectiveness of interventions aimed at improving the care of the caregivers. Also instruments must be developed that are sensitive to changes in the caregiver's and cared for person's status over time. This has not been addressed adequately in many instruments.

¹⁴³ Olson D.H, Portner J, Bell R (1982) FACES II Family adaptability and cohesion evaluation scales. Edited by: Olson, D.H., McCubbin, H.J., Barnes, H., Larsen, A., Muxen, M., Wilson, M., Family inventories: Inventories used in a national survey of families across the life cycle: St. Paul: University of Minnesota :5–24

¹⁴⁴ Deeken, JF et al (2003) Care for the Caregivers: A Review of Self-Report Instruments Developed to Measure the Burden, Needs, and Quality of Life of Informal Caregivers *Journal of Pain and Symptom Management*, 26 (4) 922–953

Appendix 4 Tables showing domains of various instruments

Three widely used standardised instruments for children and adolescents to assess individual functional status and care dependence

DOMAINS	FIM and WeeFIM FIM for children over 8 years and WeeFIM for children 6 months to 7 years and for children with developmental disabilities up to 21 years. Suitable for use with children with Autistic Spectrum Disorder	PEDI (Paediatric Evaluation of Disability Inventory) for children 6 months to 7 years & Computerized PEDI-CAT for children 0-20 years (Paediatric Evaluation of Disability Inventory Computer Adaptive Test) Some evidence PEDI-CAT suitable for children with Autistic Spectrum Disorder	VABII Birth through 90 years All Vineland-II forms aid in diagnosing and classifying intellectual and developmental disabilities and other disorders, such as autism, Asperger Syndrome, and developmental delays.
SELF-CARE	Eating, Grooming, Bathing, Dressing (Upper Body), Dressing (Lower Body) Toileting	Eating, Grooming, Bathing, Dressing (Upper Body), Dressing (Lower Body) Toileting, Independent routines	Personal Eating, dressing, personal hygiene. Domestic: What tasks the child can perform. Community: How individual uses time, money, telephone, computer, job skills.
SPHINCTER CONTROL	Bladder and Bowel Management.	Bladder and Bowel Management.	
MOBILITY MOTOR SKILLS	Transfers: Bed, Chair, Wheelchair. Toilet. Bath or Shower.	Transfers: Bed, Chair, Bath or Shower	Gross Motor: How individual uses arms & legs for movement & coordination. Fine Motor: How individual uses hands & fingers to manipulate objects

LOCOMOTION	Walking or using wheelchair, Stairs	Locomotion indoor and outdoor, Stairs	
COMMUNICAT ION	Comprehension, expression	Comprehension and expression	Receptive, expressive, written
SOCIAL COGNITION	Social Interaction, Problem Solving., Memory	Social interaction and peer play	Interpersonal Relationships, Play and Leisure Time, Coping skills
MALADAPTIVE BEHAVIOR DOMAIN			OPTIONAL Maladaptive Behaviour Index & Maladaptive Behaviour Critical Items & Adaptive Behaviour Composite of communication, daily living skills, socialization & motor skills domains.

2. Standardised instruments not widely used (and not copyrighted)

2.1. Care Dependency Scale (CDS-P)

DOMAINS	CDS-P
SELF-CARE AND DAILY ACTIVITIES	The extent 1) to which the child is able to satisfy his/her need for food and drink unaided, 2) to which the child is able to get dressed and undressed unaided 3) to which the child is able to take care of his/her personal hygiene unaided 4) to which the child is able to performe daily activities unaided e.g. clean up
SPHINCTER CONTROL	The extent to which the child is able to control the discharge of urine and faeces
MOBILITY MOTOR SKILLS	The extent to which the child is able to change his/ her position, and to take the recommended position (e.g orthopedic cases)
LOCOMOTION	The extent to which the child is able to move unaided

COMMUNICAT ION	The extent to which the child is able to communicate
SOCIAL COGNITION	The extent to which the child is able to initiate, maintain and end social contacts appropriately
DAY NIGHT PATTERN	The extent to which the child can maintain an appropriate day/night pattern unaided
BODY TEMPERATURE	The extent to which the child is able to protect his/her body temperature against external influences unaided
AVOIDANCE OF DANGER	The extent to which the child is able to assure his/her own safety unaided
SENSE OF RULES AND VALUES	The extent to which the child is able to observe rules and to respect values
PLAY AND HOBBIES	The extent to which the child is able to participate in hobbies
LEARNING ABILITY	The extent to which the child is able to acquire knowledge and/or skills and/or to retain that which was previously learned unaided

2.2. Wisconsin Children’s Long-Term Supports Functional Screen (CLTS FS)

This screen is used from birth to age 22 years determines eligibility for multiple programs having different eligibility criteria

DOMAINS	CLTS FS
DEMOGRAPHICS	Including information about living situation, legal concerns, citizenship and identify information, ethnicity and race, interpreter information, medical insurance etc
DIAGNOSES	Check all that apply

<p>MENTAL HEALTH</p>	<p>Is there a clinical diagnosis? Does child have symptoms of anorexia/bulimia, psychosis, violence, no symptoms? Does child require any of the following services – child protective services, criminal justice system, mental health services, and substance abuse services, in school supports for emotional and behavioural problems? Disruptive behaviours, Nightmares or night terrors at least 4 times a week for 6 months?</p>
<p>BEHAVIOURAL NEEDS</p>	<p>Frequency of high risk behaviours (e.g. running away, substance abuse, use of inhalants, dangerous sexual contact), self injurious behaviours (e.g. Head banging, biting oneself), aggressive or offensive Behaviour (e.g. verbal abuse, hitting, biting, kicking, serious threats of violence) and lack of behavioural controls (e.g, destruction of property/vandalism, stealing) and current interventions</p>
<p>ACTIVITIES OF DAILY LIVING (ADLS) INCLUDING SELF-CARE</p>	<p>Including age appropriate skills in bathing, dressing, grooming, mobility, transfers, eating, and toileting</p>
<p>INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLS)</p>	<p>Including, as appropriate for the child's age, communication, learning, meal preparation, and money management</p>
<p>HEALTH-RELATED SERVICES</p>	<p>Including skilled nursing tasks, therapies, and other medically-oriented interventions questions on missing over 50% of school due to health/Emergency Medical Incidents With a Sudden Onset/Bowel-related Skilled Tasks/Dialysis/Fluids or Medications/Suctioning/Respiratory Treatments/Urinary Catheter-related skilled tasks/ Total Parenteral Nutrition (TPN)/Transplant</p>
<p>WORK AND SCHOOL</p>	<p>Including info on current school/work situation, supports needed and interests for future employment Failing Grades/ Truancy High Risk Behaviours No Behaviour Problems Social Roles and Interactions Self-Injurious Behaviours Aggressive or Offensive Behaviours Violence Needs in-School Supports for emotional or behavioural problems</p>

3. Instrument under development: SIS–Child to determine support needs

DOMAINS	SIS–child
SELF-CARE	Eating Washing and keeping self clean Dressing Using the toilet Sleeping and/or napping
HOME LIVING	Keeping track of personal belongings at home Keeping self occupied during unstructured (free time) at home Operating electronic devices
COMMUNITY AND NEIGHBOURHOOD ACTIVITY	Moving around the community Participating in leisure activities that require physical activity and that do not require physical exertion Using public services in community Participating in community service and religious activities Attending special events in the community such as cookouts/picnics, cultural festivals, music/art fairs, or holiday oriented events
PARTICIPATION ACTIVITIES	Being included in general education classrooms Participating in activities in common school areas Participating in co-curricular activities Getting to school (includes transportation) Moving around within the school and transitioning between activities Participating in large-scale test taking activities required by state education systems. Following classroom and school rules Keeping track of personal belongings at school Keeping track of schedule at school
SCHOOL LEARNING ACTIVITIES	Accessing grade level curriculum content Learning academic skills Learning and using metacognitive strategies Completing academic tasks Learning how to use and using educational materials, technologies, and tools Learning how to use and using problem solving and self-regulation strategies in the classroom Participating in classroom evaluations, such as tests Accessing the health and physical education curricula Completing homework assignments
HEALTH AND SAFETY ACTIVITY	Communicating health related issues and medical problems, including aches and pains Maintaining physical fitness – emotional well-being –health and wellness – implementing routine first aid when experiencing minor injuries such as a bloody nose – responding in emergency situations –protecting self from physical, verbal, and/or sexual abuse – avoiding health and safety hazards
SOCIAL ACTIVITIES	Maintaining positive relationships with others Respecting the rights of others Maintaining conversation Responding to and providing constructive criticism Coping with changes in routines and/or transitions across social situations Making and keeping friends Communicating with others in social situations Respecting others personal space/property Protecting self from exploitation

	and bullying
ADVOCACY ACTIVITIES	Expressing preferences Setting personal goals Taking action and attaining goals Making choices and decisions Advocating for and assisting others Learning and using self-advocacy skills Communicating personal wants and needs Participating in educational decision making Learning and using problem solving and self regulation strategies in the home and community

4. Functional Status II Questionnaire (does not measure care dependence)

While this can measure health status across a wide age range it is especially suitable for children with chronic physical (not mental) conditions who do not have a disability

	Part 1			Part 2 (Was this		
due to illness)						
Did your child...	Never or <u>rarely</u>	Some of <u>the time</u>	Almost <u>always</u>	Fully	Partly	Not <u>at all</u>
A. Eat well	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
B. Sleep well	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
C. Seem contented and cheerful	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
D. Act moody	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
E. Communicate what (he/she) wanted	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
F. Seem to feel sick and tired	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
G. Occupy (him/herself)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀

H. Seem lively and energetic	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
I. Seem unusually irritable or cross	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
J. Sleep through the night	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
K. Respond to your attention	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
L. Seem unusually difficult	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
M. Seem interested in what was going on around (him/her)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
N. React to little things by crying	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀

5. Measuring Severity Autism Spectrum Disorder (as opposed to Autism Screening Tools)

The following are the common measures. The following is taken from “Defining and Quantifying Severity of Impairment in Autism Spectrum Disorders Across the Lifespan” by Katherine Oberle Gotham A dissertation submitted in partial fulfilment of the requirements of the degree of Doctor of Philosophy (Psychology) in The University of Michigan 2010 Accessible at http://deepblue.lib.umich.edu/bitstream/2027.42/77759/1/kog_1.pdf

Measures that provide autism severity ratings that tend to yield scores that are either strongly correlated with IQ or that do not correspond to standard measures of diagnosis (Gilliam, 1995; Volkmar et al., 1988; Spiker, Lotspeich, Dimiceli, Myers, & Risch, 2002; South et al., 2002; Szatmari, Bryson, Boyle, Streiner, & Duku, 2003) include

4. **The Childhood Autism Rating Scale** (CARS; Schopler, Reichler, & Renner, 1986)

5. **The Gilliam Autism Rating Scale** (GARS; Gilliam, 1995)

6. **The Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1980),**
7. **Social Responsiveness Scale (SRS) (SRS; Constantino et al., 2003)** provides a method for quantifying social impairment that has shown relative independence from participant characteristics such as IQ. SRS scores are based on parent or teacher report, however, and thus a complementary measure of ASD severity that offers the opportunity to take into account the observations of an experienced clinician would be desirable.

For genetic, neuroscience, and intervention research, severity of core autism features often has been estimated using primary phenotyping measures

8. **The Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000)** The ADOS, a semi-structured autism diagnostic observation, has shown strong predictive validity against best estimate diagnoses (Gotham, Risi, Pickles, & Lord, 2007), making it a common choice among phenotyping measures. Because the ADOS has been used to catalogue ASD features in large samples, ADOS raw totals are a common standard for a measure of autism severity. This instrument was created for diagnostic purposes
9. **The Autism Diagnostic Interview-Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003).**

6. Tools used for Autism Screening

These include CHAT, M-CHAT, the Early Screener for Autistic Traits, The Social Communication Questionnaire (SCQ), the Developmental Behaviour Checklist – Early Screen, the Communication and Symbolic Behaviour

Scale – Developmental Profile (CSBS–DP), The Pervasive Developmental Disorders Screening Test, the Screening Tool for Autism in Two Year Olds¹⁴⁵.

7. Multidimensional child and adolescent generic measures of health outcomes encompassing functional, health status and health related quality of life for use with general populations of children and adolescents (do not measure dependence per se)

Patient Reported Health Instruments Group: Instruments for Children and Adolescents: A review by Schmidt, Garratt and Fitzpatrick (2001) Accessible at http://phi.uhce.ox.ac.uk/pdf/phig_children_report.pdf

¹⁴⁵ Barton, M., Chlebowski, C., Fein, D. Screening for Autism Spectrum Disorders in Young Children: A review of the literature. Accessible at <http://www.ncnp.gov/nimh/jidou/join/review.pdf>

This report presents a review of multi-dimensional generic measures of child/parent-reported health outcomes (encompassing functional, health status, and health-related quality of life measures) for use with general populations of children and adolescents.

The literature search identified ten reviews of instruments for use with children or adolescents, none of which focussed on applications at the population level. One comprehensive and systematic review of measures for children with chronic diseases was identified.

16 generic and multi-dimensional instruments which had been evaluated in a general population of children or adolescents were identified. Three of these had been developed in the UK. Most instruments cover the three main areas of physical, social and mental health and well-being; some also address school achievement, family functioning and risk-taking behaviour.

Several child-completed instruments were identified for use with young children (from the age of six), although parent-completed measures were common for this and younger age-groups. For older children (aged 11 and over), the majority of instruments identified were self-completed. Four parent-completed instruments can be used with children under one year old, whilst child-completed instruments have been developed for children as young as four.

Only five instruments have reported data on both internal consistency and test-retest reliability in general populations. All except two instruments have undergone some testing for construct validity.

In choosing a particular instrument, the nature and design of the instrument should be assessed against the prospective application. One needs to be clear whether a parent- or child-response is preferred, which domains are of most relevance, and what degree of prior testing of the instrument is acceptable.

Table 1: Only the three instruments recommended by the authors of the 2001 review are shown below (These are taken from Tables III and IV of the summary report which is available at http://phi.uhce.ox.ac.uk/pdf/phig_children_summary.pdf)

Instrument	Aim/intended application	Dimensions (no. of items)
<p>Child Health and Illness</p> <p>Profile/CHIP-AE</p>	<p>To document state of health in adolescent populations, identify differences in health of sub-populations, assess impact of health service interventions on health, make initial assessment of adolescents for screening services. <i>Modified CHIP-AE is specifically modified for assessing adolescent health behaviours to inform school health programme planning.</i></p>	<p>Satisfaction with health – overall health and self-esteem (12); discomfort – physical and emotional symptoms, limitations of activity: boys (44), girls ([45]; achievement – academic and work performance (11); risks – individual risks, threats to achievement, peer influences (39); resilience – family involvement, problem-solving, physical activity (20); disorders – conditions (45); home safety and health (12)</p> <p>CHIP taxonomy: satisfaction, discomfort, risks and resilience</p> <p>Modified CHIP-AE excludes limitations of activity, work performance, home safety and health, recurrent disorders, long-term medical and surgical disorders, psychosocial disorders.</p>
<p>Child Health Questionnaire/ CHQ – parent-completed</p>	<p>To measure and compare health of general and specific groups of children; to evaluate treatments.</p>	<p>General health perceptions (6); physical functioning (6); bodily pain (2); role/social-physical (2); role/social-emotional-behavioural (3); mental health (5); behaviour (6); self-esteem (6); parental impact-emotional (3); parental impact-time (3); family activities (6); family cohesion (1); change in health (1)</p>
<p>Child Health Questionnaire/ CHQ – child-completed</p>	<p>as above</p>	<p>General health perceptions (12); physical functioning (9); bodily pain (2); role/social-physical (3); role/social-emotional (3); role/social-behaviour (3); mental health (16); behaviour (17); self-esteem (14); family activities (6); family cohesion (1); change in health (1)</p>
<p>Warwick Child Health and</p>	<p>Measure of health and morbidity suitable for research, service-planning, measuring cross-sectional and</p>	<p>General health status (1); acute minor illness status (1); behavioural status (1); accident status (1); acute significant illness status (1); hospital admission status (1); immunization status (1);</p>

Morbidity Profile	longitudinal health and morbidity.	chronic illness status (1); functional health status (1); health-related quality of life (1)
-------------------	------------------------------------	--

Table II: The 10 reviews of instruments for children and adolescents from which the 3 instruments above were identified

Review and Aim if specified	Databases and Search terms	Inclusion criteria	Evaluative criteria	Instruments identified	Recommendations
Bullinger & Ravens-Sieberer, 1995	Searched Medline, Embase, Psycinfo, Psycocom, Cancerlit, Aidsline, Bioethicsline & Somed 1964-1995. Used terms 'quality of life' & 'child'. Weighting system used but not clear what.		Descriptive: age, respondent, number of scales, target population, reliability, validity, sensitivity.	Measures of function: NIE Functional Status Index, Functional Status (II)R, Batelle Developmental Inventory, Vineland Adaptive Behavior Scales, Play Performance Scale for Children, Wee-FIM, Pediatric Evaluation of Disability Inventory. Generic quality of life instruments: Ontario Child Health Study, CHQ, Children's Health Rating Scales, Quality of Well-being scale, General Health Rating Index, NICQL, QoL index for Nordic countries.	
Colver & Jessen, 2000 To identify generic measures in English which either have been	Not explicit		Descriptive: mode of administration, age, respondent, reliability, validity	Functional health status instruments: Vineland Adaptive Behaviour Scale, WeeFIM, HUI Mark II & III. Measures of health status/QOL: CHQ, Children's Quality of Life Scale, PedsQL, TACQOL, KINDL, Adolescent Quality of Life Profile.	Comments that the best instrument is the CHQ, although the PedsQL is shorter & has advantage of seeking the views of children from age 5.

or could be used in neonatal follow-up studies.					HUI3 useful for economic evaluations.
Connolly & Johnson, 1999 To provide an overview of generic HRQOL measures used in paediatric populations.	Searched Medline, HealthSTAR & Embase 1980-1988. Used terms 'quality of life', 'paediatrics', 'child*' & 'adolescent'.	Instruments focus on measurement of health-related quality of life for use in paediatric populations with evidence of its use & results.	Descriptive: domains, respondent, age, number of items, mode of administration, country/language, translations, population, reliability, validity.	CHIP-AE, CHQ, COOP, DUCATQOL, Functional Status (II)R, KINDL, Nordic Quality of Life Questionnaire for Children, Ontario Child Health Study, Rand Health Status Measures for Children, TACQOL, WCHMP, 16D, 17D. Preference-based measures: HUI Mark II & III, QWB Scale.	
Eiser & Morse, 2001 a & b To identify currently available generic & disease-specific measures of quality of life for children with chronic diseases.	Searched Medline, BIDS ISI Science Citation Index, BIDS ISI Social Science Citation Index, PsycInfo, Cochrane Controlled Trials Register & meta-Register of Controlled Trials for English language papers 1980-1999. Used terms 'functional status', 'health status', 'quality of life', 'chronic diseases', 'illness' & individual chronic diseases. Hand searching & checking of	Included if measure of quality of life, health status or well-being in children aged 18 or under with a chronic disease. Measures had to include some reliability or validity data & be used by child, proxy or both.	Descriptive: respondent, age, number of domains, number of items, reliability, validity, origin.	CHIP, CHQ, Child Quality of Life Questionnaire, COOP, Exeter Quality of Life Measure, Functional Status (II)R, Generic Health Questionnaire, How Are You?, KINDL, Nordic Quality of Life Questionnaire for Children, Pediatric Quality of Life Questionnaire, Perceived Illness Experience, Quality of Life Profile-Adolescent Version, SIP, TACQOL, Warwick Child Health & Morbidity Profile, HUI Mark II & III, 16D, 17D, Quality of Well-Being.	Three instruments fulfil basic psychometric criteria: CHQ, Pediatric Quality of Life Questionnaire, HUI Mark II (though the last two are not designed to assess the full range of functioning).

	reference lists.				
Kozinetz et al., 1999 To identify reliable & valid instruments for measuring the health status of children with special care needs in the clinical setting.	Searched Medline 1966–1988 for English language papers using terms ‘health status’, ‘quality of life’, ‘outcome assessment’, ‘functional status’ & ‘patient satisfaction’.		Descriptive: purpose, respondent, timing of use, reliability/validity, mode of administration, clinical use.	Measures of health status: Rand Health Status Measures for Children, HUI, CHIP–AE, HUI Mark II, CHQ. Four measures of satisfaction with care. Measures of satisfaction with health status: Feeling Thermometer, Standard Gamble. Functional status measures: Basic Gross Motor Assessment, Functional Independence Measure for Children (WeeFIM), Functional Status II(R), Play Performance Scale for Children. Measure of family health status: Impact on Family Scale.	Comments that only the CHQ has information relating to responsiveness in clinical care.
Landgraf & Abetz, 1996 To identify instruments developed & validated specifically for paediatric populations.	Extensive search of psychological & medical literature using terms ‘quality of life’, ‘health status indicators’, ‘generic health surveys’, ‘health outcomes’, ‘outcomes assessment’ & ‘activities of daily living’.		Descriptive: purpose, age, respondent, mode of administration, number of items, psychometric results.	CHIP, COOP, Functional Status II(R), Health Institute’s Child Health Assessment Project, Rand Health Status Measures for Children, National Health Interview Survey, Ontario Child Health Study, Quality of Well-Being Scale	
Levi & Drotar, 1998			Descriptive: domain, age, respondent, specific conditions.	CHIP, CHQ Rand Health Status Measures for Children, HUI Mark II, Quality of Well-Being scale. Six functional status measures: Child Health Assessment Questionnaire, Functional Disability	

				Inventory, WeeFIM, Functional Status II(R), PEDI, Play Performance Scale for Children.	
Marra et al., 1996 To identify recent work in producing multi-dimensional measures of HRQOL for children & adolescents.			Descriptive: domains	Rand Health Status Measures for Children, CHIP-AE, Functional Status (II)R, MAHS, Vineland Adaptive Behaviour Scale, Paediatric Evaluation of Disability Inventory, Play Performance Scale for Children.	CHIP, FS II (R), Rand Health Status Measures for Children
Pal, 1996	No terms given but searched Medline, Embase & SciSearch 1979-199	Instruments assessed according to criterion of 'child-centredness' & extent to which child considered part of 'family unit within a social network'; had to be 'generalisable' & have 'appropriate underlying assumptions'.	Descriptive: age, dimensions, method of administration, psychometric characteristics, scoring, statistical issues & practicality.	Rand Health Status Measures for Children, Functional Status II(R), MASC, CHIP-AE, Nordic Quality of Life Questionnaire, Child Quality of Life Questionnaire, FSQ, instruments by Austin (1994) & Schmidt (1993).	

Spieth & Harris, 1995	No details of search terms or databases used	Measures included if covered 4 core components of QoL: disease status, functional status, social and psychological functioning	Descriptive: domains, respondent, age, number of items, psychometric properties, disease-specific populations.	Play Performance Scale for Children, Quality of Well Being Scale, Rand Health Status Measures for Children, CHIP.	
-----------------------	--	--	--	---	--

Appendix 5 Psychometric Properties of WeeFim and other instruments

This table reproduces the results for the psychometric properties of the FIM and the other scales that scored highest in quality from 17 physical disability scales included in a chapter on scales for measuring physical disability and functioning in the 2006 Oxford University Press Edition of *Measuring Health: A Guide to rating scales and Questionnaires* by McDowell

Instrument	Scale	Number of Items	Application	Administered by (Duration)	Studies using method	Reliability, thoroughness	Reliability, results	Validity, thoroughness	Validity, results
FIM (Granger & Hamilton, 1987)	Ordinal	18	Clinical	Expert, interviewer	Many	**	***	***	***
HAQ (Fries, 1980)	ordinal	20	Clinical, research	Self, staff (5-8 mins)	Many	***	***	***	***
Barthel Index (Mahoney	ordinal	10	Clinical	Staff	Many	***	***	***	**

Instrument	Scale	Number of Items	Application	Administered by (Duration)	Studies using method	Reliability, thoroughness	Reliability, results	Validity, thoroughness	Validity, results
and Barthel, 1955)									
Functional Autonomy System (Herbert 1984)	Ordinal	29	Clinical	Staff 40 mins	Several	**	**	**	***
Functional Status Index (Jette 1980)	Ordinal	54	Clinical	Interviewer	Several	**	**	**	**
OECD Disability Questionnaire (OECD,	ordinal	30	Clinical	Staff	few	*	**	*	*

Instrument	Scale	Number of Items	Application	Administered by (Duration)	Studies using method	Reliability, thoroughness	Reliability, results	Validity, thoroughness	Validity, results
1981)									