

**Guidance to Support the
Allocation of Care
within Children's Hospice &
Palliative Care Services:**

**A draft document for
comments**

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We would like to acknowledge the members of the Together for Short Lives Leaders of Care Group who responded to the national consultation.

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INTRODUCTION

Purpose of this document

This guidance aims to help children's hospice and palliative care services to develop and implement a needs assessment process which ensures that there is a transparent, needs-led system which defines all care and support available to children young people and families. It has been created to enable children's hospices and palliative care providers to explore their individual challenges with regard to the use of their resources and to consider solutions to meet these.

It has been developed to inform and enhance current practice and is underpinned by a set of evidence based principles, which were agreed at a series of workshops held to examine the current approaches to the allocation of care currently used within children's hospice and palliative care settings. We have developed this document as a starting point. It builds on the experience of many children's hospices in addressing the issue of care allocation. We would welcome further views from other children's hospices and wider children's palliative care services. We will be contacting Leaders of Care in children's hospice and palliative care early in 2015 for specific feedback, but if you have any comments in the meantime please email them to Dot.Gillespie@donnalouisetrust.org

The guidance is intended for use with children and young people who have met the eligibility criteria for children's hospice and palliative care services.

It is hoped that the guidance will also be used to assist referrers and commissioners to understand the breadth of services offered to children, young people and families to ensure that they receive the right care, at the right time and in the right place for them, facilitating and sustaining early support for families. It is important to recognise that children's hospices in particular have moved from being providers of short-break care to being providers of specialist palliative care services for children with life limiting conditions and their families, with short break care as one element of this.

It is important to make sure that any tools and systems used to assess needs and allocate care are communicated well, not only to the families, but also to other professionals working with the families or referring children to children's palliative care services.

This document aims to provide guidance and information on the following:

- Up to date evidence to support decision making
- Ensuring equitable access to services
- Enabling objective, consistent and fair allocation of resources, which meet identified outcomes
- Achieving standardised assessment of needs within an organisation
- The principles to be considered when developing tools for assessing need
- Examples of tools for assessing need and using the assessment to inform decisions on the allocation of care
- Facilitating discussion with, and the involvement of families
- Alternative models for allocating care resources which are agreed in partnership with families and manage family expectations

BACKGROUND AND CONTEXT

The growth in the number of children's hospice and palliative care services with shared boundaries has created an important opportunity to work together to avoid duplication and provide an equitable service for families based on assessed need. There are many challenges facing children's hospice and palliative care service providers, in ensuring that resources are used effectively to meet increasing demand, assessed need and identified outcomes.

For example, in England, all children's palliative care services will need to be prepared to take into account the reforms within the Children and Families Act 2014 and The Care Act 2014. These two pieces of legislation will bring about a significant change to the way that education, health and social care is delivered for children and young people with special educational needs and disability. These reforms focus on the following themes:

- Working towards clearly defined outcomes
- Engagement and participation of parents and young people
- Joint Commissioning and developing a Local Offer of support
- Coordinated assessments and Education, Health and Care Plans
- Personalisation and personal budgets

The majority of children's palliative care services have seen both an increase in the number of children, young people and families referred to their services and an increase in the level of complexity of needs of the children and young people. This is supported by clear evidence that the numbers of children living with life-limiting and life-threatening conditions are much higher than previously thought (Fraser et. al 2012 and 2014).

In addition to these changing demographics the increase in demand has also been influenced by:

- cuts in other public services
- an increase in awareness of the support provided by children's palliative care among families and professionals
- an increased policy focus on children with disabilities and additional needs
- an increased media and public interest in end of life care, illustrated by the significant interest in the Liverpool Care Pathway
- Implementation of personal budgets, increasing use of direct payments and the potential national tariff

All of these have raised the profile of palliative and end of life care and the need for transparent, individualised systems of care.

Facing these challenges and creating a workforce fit for purpose will ensure that every family will have access to sustainable, holistic, family-centred and high quality palliative care whenever and wherever they need it, see Appendix 1.

A REVIEW OF THE LITERATURE REGARDING NEEDS ASSESSMENT TOOLS

A review of the literature (see Appendix 2) revealed very little research evidence directly related to the assessment of needs in a children's palliative care setting. The literature

review provided information relating to a number of assessment tools that have been developed in a wide range of settings for a wide range of patients but few of the assessment tools were appropriate for use within a children's palliative care service.

Many of the studies reviewed included an assessment to help with the allocation of short break care; the assessment of dependency of individuals for nursing and medical interventions - a symptom orientated and medical model approach. None of them incorporated a holistic approach to understanding, identifying and assessing the needs of the child and family members, in line with the philosophy of children's hospice and palliative care.

Personalisation and person centred planning is the driver for any assessment process. The development of an outcomes based service is central to the parents, carers, children and young people.

The level of support required by each family will vary and may change quickly. It is often dependent upon their own resilience, the psychosocial dynamics and emotional needs in the family, other networks of support in place as well as the child's own physical care requirements.

BENEFITS AND BARRIERS OF USING AN ASSESSMENT TOOL

The following lists of benefits and barriers to using an assessment tool were developed following a workshop with children's palliative care leads held in June 2013 and a review of the evidence base.

Benefits of using a needs assessment tool

- Improves the content and comprehensiveness of assessment.
- Assists staff in making consistent, holistic assessments.
- Can be used for monitoring and auditing service allocation.
- Assists in strategic and service planning, identifying gaps in service delivery and provide thorough and accurate information about the needs of this population of children and families.
- Improves communication with the child and family and between professionals, reducing the need for replication of assessments.
- Enables detailed discussions to take place with children, young people and families about complex issues.

Potential Barriers to the use of an assessment tool

- *Time* – the time required to complete the assessment paperwork may be a factor in resistance to implementation by health professionals. This can lead to poor compliance and poor documentation.

- *Clinical judgement* – the tool or approach may not be viewed as an alternative to clinical judgement. A considerable degree of clinical judgement was still required to interpret an assessment.
- *Training* – health professionals required specific training to carry out an assessment and to respond to needs identified.
- *Compatibility* – the tool or approach was difficult to integrate into other assessment practices and IT systems.
- *Content* – the content of the tool or approach was seen as too simplistic or not comprehensive enough, with further assessment still being required.
- *Lack of family focus* - lack of child and family focus and engagement.
- *Fatigue* – the tool or approach was too long and unwieldy to be acceptable to children and families.
- *Validity* – the tool or approach was not validated.
- *Professional communication* – the assessment was not shared between individuals involved in care, either between disciplines or agencies.
- *Lack of IT solutions* - lack of interagency IT solutions acted as a barrier to sharing assessment information.
- *Leadership* - lack of an organisational lead or champion.

THINGS TO THINK ABOUT BEFORE YOU START

The following list provides a checklist of areas to consider before any new assessment or allocation of care tool is introduced:

- Do you have clear eligibility criteria?
- Is there clarity about what services your organisation provides, your organisation's priorities for care and resources available?
- Are you aware of how your service fits with other services provided in your area and with the Local Offer of services for disabled children and young people?
- Do you know how your service will link in with Education Health and Care plans?
- How will needs be assessed in a comprehensive, person centred way? This may include more than one assessment tool, e.g. Holistic Needs Assessment, Distress Thermometer or a short breaks assessment tool
- How will the assessment identify outcomes for the child or young person and their family and how will they be matched with available resources (this could be another care provider)?

- Is there agreement about who else needs to be involved i.e. other key professionals involved with the child and family?
- What is the timeframe from assessment to decision making?

EVALUATING YOUR CURRENT APPROACHES

1. What do you currently do – why? What evidence is this based on?
2. What are your priorities for care?
3. Are decisions about allocation of care based on assessed needs?
4. Are there identified outcomes?
5. What do you currently do that works for both families and the organisation? How do you know it works?
6. What services do you currently offer?
7. Are you developing any new services that will need to be taken into consideration in the allocation?
8. What do your local commissioners understand about your service?
9. How do you work with your local commissioners?
10. Resources. What is the position of the organisation, does it function on a resources required or a resources available model?
11. What family involvement is there in the allocation model?
12. What family involvement does the organisation want?
13. Are you aware of other assessment s for the child and family and how or do you incorporate this information?

DEVELOPING AN ASSESSMENT TOOL

Developing or identifying an assessment tool to meet the needs of the organisation can be a daunting task. There are examples of some needs based assessment tools in the appendices for your consideration.

However, if you are looking to develop your own tool you may find it helpful to consider some of the key criteria below, which were identified at a Together for Short Lives workshop in June 2012. At this workshop it was identified that assessment tools need to be:

- To be informed by the evidence base
- To have an agreed process for local testing and validation
- To be auditable

- To be user friendly
- To reflect multi professional involvement
- To be capable of reflecting the level of need including areas of complexity and risk
- To have the ability to inform resource planning and be used to structure resource allocation and give an account of reasoning behind the decision.
- To encompass all care provision – not just ‘in house’ bed nights
- To relate to admission / referral criteria
- To inform plan of care
- To be consistently interpreted and applied
- To have decision making guidance that is flexible and leaves room for professional judgement
- To provide clear guidance on how often and when to re-assess
- To seek service user feedback. Some services have tools which enable families to self-assess their needs (Jessie May Trust, 2010. Guidance for respite in partnership with families.)
- To identify areas of priority – for example, end of life care, symptom management, short breaks, emotional support need, transition

KEY FEATURES OF AN ASSESSMENT TOOL

There are limitations to using tick box assessment tools and the use of closed questions (Munroe 2011). Assessment Tools should be designed to use guided conversation to consistently capture the family story, expectations and desired outcomes, differentiating between wants and needs. This in turn will inform the decision making and plan of care for each child/young person and family member.

An effective tool will capture the holistic needs of the child/young person and family including:

- health needs of the child/young person
- social factors
- emotional health and wellbeing
- the support networks in place both formal and informal
- school attendance
- family dynamic
- frequency of hospital admissions
- family resilience
- siblings, parents and significant others
- sleep deprivation
- safeguarding concerns
- choices and preferences of when and where care could be received
- hopes and wishes and advanced care planning
- need for specialist/ palliative care input

Examples of some assessment tools commonly used across children’s services and adult palliative care include the adult palliative care assessment tool known as PEPSI COLA,

which can be found at www.mvcnprof.nhs.uk and the national Common Assessment Guidance (CAF Plus) which can be found at www.education.gov.uk.

Other assessment tools that may be useful sources of information are:

- The NHS Lothian, 2010. Children's continuing healthcare assessment tool (CCHAT). NHS Scotland <http://www.cen.scot.nhs.uk/care-packages>
- The Northern Ireland Regional Nursing Assessment Tool, available at: http://www.dhsspsni.gov.uk/developing_services_to_children_july_2009.pdf
- National Guidance for Children and Young People's Continuing Care Decision Support Tool, available at <http://www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/continuing-care-children.aspx>
- Leeds Nursing dependency score available at www.rcn.publishing.com

WHO SHOULD COMPLETE THE ASSESSMENT?

This will differ between organisations. When considering who should carry out assessments take into account competence of the staff including:

- Assessment skills
- Communications skills
- Outcome/ goal setting skills
- Knowledge and understanding of the purpose of the tool
- Knowledge of services available from the organisation and others
- Knowledge of outcome based interventions

DECISION MAKING

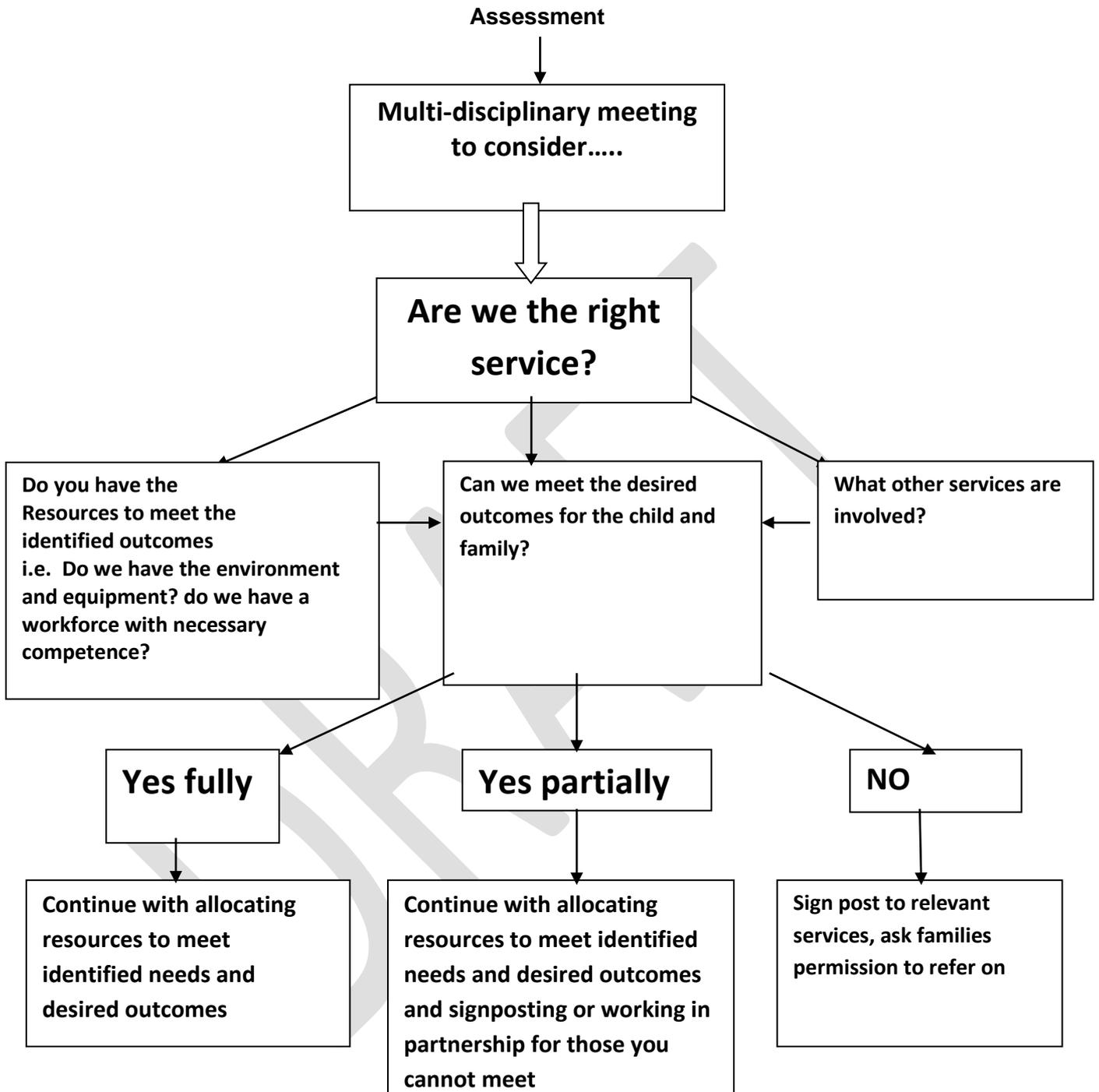
Decisions related to the allocation of care for children, young people and families should be a multi-disciplinary process. The use of a structured feedback approach to support consistent decision making should also be considered.

There are a number of models used in the sector to inform the type and level of services offered to children and families and to enable transparent decisions to be made. These fall into four main categories:

- Outcome based model
- Scoring based model
- Resource based model
- Service specific model

Examples of these different models can be viewed in Appendix 3.

DECISION MAKING FRAMEWORK



THE NEXT STEPS

As you consider the full implementation phase of a new allocation of care system, it will be important to think about the following:

1. Will there be a shift in the values and principles of the organisation that will need to be addressed if you change your allocations system?
2. Does the Trust Board support the proposed implementation of your approach to allocation of services?
3. What resources are needed to develop and implement a new approach?
4. What will be needed in terms of a robust change management approach, for example:
 - Think about the impact of the changes to existing families, workforce and other stakeholders
 - Identify training needs and develop training programmes in response
 - Manage expectations of all stakeholders as part of the change management process
 - Develop a communication strategy – internal and external
 - Ensure robust project management

Workforce Considerations

Workforce development is needed to directly support children's hospice and palliative care services to recruit and retain the right skill mix to build a workforce that can provide the very best quality of care for children and families today, tomorrow and into the future.

The need for a whole range of skills from novice to expert is essential in palliative care of children as it often involves care from the most simple to very complex, including rare conditions. This complexity requires accomplished high level skills, not only in the practical application of theory, for example, in the administration of medicines and provision of psychosocial support, but also an ability to communicate with children and families at all levels and to work within and across diverse populations while recognising the uniqueness of the individuals they are caring for.

The right care at the right time is crucial to every seriously ill child and family member makes a real difference to the quality of their life and that of their family. A flexible, compassionate, committed and highly skilled workforce is therefore key to providing the very best care and support.

There is a growing need for the hospice and palliative care workforce to become increasingly flexible, to work across many different settings in response to the changing needs and preference of children with life-threatening conditions and their families.

The recent Commission on the Future of Hospice Care endorsed that there is a clear mandate for a strategic approach to workforce development; it is in the top 3 strategic priorities highlighted by the Commission's work. Recent policy initiatives and legislative changes will have a significant impact on how future services will be organised and delivered in all four countries of the UK. Workforce readiness and development for children's hospice services is a crucial part of preparing them to meet these changes with confidence.

Examples of workforce challenges:

- Recruitment across a skill mix
- Retention of key staff
- Succession planning to ensure continuity of services
- Use of competency guidance
- A sustainable medical workforce
- Leadership support and development
- Mentorship and preceptorship

EACH Library - Literature Search

Title: Assessment of need and tools used to allocate resources

Requested by: Tracy Rennie

Completed by: Sue Langley - 8th October 2013.

Resources Searched:

Healthcare Databases: MEDLINE, EMBASE, CINAHL, British Nursing Index (BNI), and Health

Management Information Consortium (HMIC)

Internet: NICE Evidence, Google.

Tools

Department of Health, 2010. NHS Framework for children and young people's continuing care. DH. Appendix A: Assessment toolkit using the Decision Support Tool, see pages 29-53.

Available at:

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_116469.pdf [viewed 3/10/2013]

Department of Health, Social Services and Public Safety, Northern Ireland. 2009. Developing services to children and young people with complex physical healthcare needs. DHSSPS. Appendix 1: Regional Nursing Assessment Tool – see pages 60 – 80.

Available at:

http://www.dhsspsni.gov.uk/developing_services_to_children_july_2009.pdf [viewed 3/10/2013]

NHS Lothian, 2010. Children's continuing healthcare assessment tool (CCHAT). NHS Scotland

CCHAT is a tool to be used alongside a comprehensive assessment of child and family wishes and needs, and professional judgment. The purpose of the Tool is to support professional decision making by giving an 'objective' estimate of the number of hours that health should contribute to a care package. The Tool has two components, the CCHAT Assessment used to collect information from professionals who know the health needs of a child, and CCHAT Scoring which uses the assessment to estimate the support needed.

Available as a Word Document with attached guidance.

Jessie May Trust, 2010. Framework for respite in partnership with families (FRIPP). The tool was evaluated by Dr Nicola Eaton, University of West of England in 2009 – this has been requested from Dr Eaton via email. The FRIPP tool has also been published in *Nursing Children and Young People*, 2011 – see abstract section for more details.

Richardson, A., Medina, J., Richardson, A., Sitzia, J. & Brown, V. 2005. *Patient's needs assessment tools in cancer care: principles and practice*. Kings College, London.

This report looks at the principles of needs assessment, and reports on a total of 15 tools used by Cancer Networks to assess need and care provision.

Available at: <http://www.kcl.ac.uk/teares/nmvc/external/docs/ar-patients-needs-assessment-final.pdf>
[viewed 03/10/2013]

Children with exceptional needs (CEN) Scotland. 2005. *National need assessment tool for long term ventilated children in the community*. 2nd edition. Available as a Word Document – adapted from the Bradford Continuing Care tool.

Escolme D. and James, C. 2004. *Assessing respite provision: the Leeds nursing dependency score*. Published in *Paediatric Nursing*, 16 (2) 27 – 31.

Available at: <http://rcnpublishing.com/doi/pdfplus/10.7748/paed2004.03.16.2.27.c898>

Guides and Reports – general overviews on assessment

Royal College of Nursing, 2007. *Research and Practice Briefing. Assessing the needs of children and families*. Provides an overview of assessment, and discusses the Common Assessment Framework.

Available at:
http://www.rcn.org.uk/__data/assets/pdf_file/0005/438413/Assessing_the_needs.pdf

Newman, T. 2009. *Disability Research Review 3: Ensuring all disabled children and young people and their families receive services which are sufficiently differentiated to meet their diverse needs. An analysis of the existing knowledge and evidence*. The Centre for Excellence and Outcomes in Children and Young People's Services (C4EO). This will be updated as the theme progresses. Section 5: *What the literature tells us about the specific additional needs of particular groups of disabled children* – pages 17 – 33.

Available at:
http://www.c4eo.org.uk/themes/disabledchildren/diverseneeds/files/c4eo_diverse_needs_kr_6.pdf
[viewed 03/10/2013]

Kellett, J. & Apps J. 2009. *Assessment of parents and parenting support needs: a study of*

four professional groups. Joseph Rowntree Foundation. The report looks at the processes used to assess parenting need.

Available at: <http://www.jrf.org.uk/sites/files/jrf/parenting-support-need-full.pdf> [viewed 07/10/2013]

Cavanagh, S. & Chadwick J. 2005. Health Needs Assessment: a practical guide. NICE.

The purpose of this guide is to provide practical assistance to everyone engaged in undertaking HNA, including strategic managers at regional and local levels, facilitators, and practitioners in primary care trusts, local government and the voluntary and community sectors. The guide describes the systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities.

Available at:

http://www.nice.org.uk/media/150/35/Health_Needs_Assessment_A_Practical_Guide.pdf [viewed 03/10/2013]

Journal Articles

Title: Validity and reliability of the Japanese version of the family needs survey

Citation: Research in Developmental Disabilities, October 2013, vol./is. 34/10(3596-3606), 0891-4222; 1873-3379 (October 2013)

Author(s): Ueda K., Bailey D.B., Yonemoto N., Kajikawa K., Nishigami Y., Narisawa S., Nishiwaki M., Shibata M., Tomiwa K., Matsushita A., Fujie N., Kodama K.

Abstract: Early intervention and disability services in Japan historically have focused on supporting the individual with a disability, with only secondary attention to family needs and priorities. Since the Basic Law for Persons with Disabilities was codified in 2011, the Japanese government has been responsible for supporting families with members who have disabilities. To assess the needs of these families, we evaluated the reliability and validity of the Family Needs Survey (FNS), initially developed in 1988 (Bailey & Simeonsson), to determine its usefulness for programs providing services for Japanese families who have a child with a disability. The FNS is a practical tool to assess family needs and is already used across many different cultures and populations. To evaluate the reliability and validity of the FNS, we conducted an anonymous survey with a self-administered questionnaire at 6 treatment and education institutions, 3 medical institutions mainly for children with disabilities, and 39 special needs schools in the Osaka area. We analyzed 1171 parents' survey responses: 452 fathers and 719 mothers of children with disabilities aged 0-15 years old who answered all items on the Japanese version of the FNS. Another survey was administered to 130 specialists who work with children with disabilities to assess the content validity of the Japanese version of the FNS. We verified the factor structure, content validity, and reliability of the Japanese version of the FNS as an assessment tool with 34 items among four factors that were based on the same items in the original FNS. The assessment

could be used for families with school-age children as well as younger children, in contrast to the original version, which is not appropriate for school-age children. We also confirmed that it could be used without regard to type or degree of disability. 2013 Elsevier Ltd.

Source: EMBASE

Title: Use of the common assessment framework in an acute setting

Citation: *Nursing Children & Young People*, Jun 2013, vol. 25, no. 5, p. 24-28, 2046-2336 (June 2013)

Author(s): Powell, Jane

Abstract: Research suggests that use of the common assessment framework (CAF) assists in the early identification of, and response to, clients' needs. CAF is used to promote early intervention and effective multi-agency working, particularly with children who have additional needs. The holistic process includes good information sharing and well co-ordinated plans, in partnership with service users, families and other agencies. CAF was launched at an acute children's hospital more than five years ago. However, it was not established successfully as part of routine practice until a CAF lead was appointed in recognition of the awareness, training and support that staff require to use the tool effectively, resulting in notable improvement in CAF activity and client outcomes.

Full text available from EBSCO host in *Nursing Children and Young People*

Title: Introduction of a new tool to help assess parental needs surrounding the death of a child: Will this help us do better?

Citation: *Critical Care Medicine*, November 2012, vol./is. 40/11(3103-3104), 0090-3493; 1530-0293 (November 2012)

Author(s): Das S.K.

Full text available from Ovid in *Critical Care Medicine*

Title: Partnership working in services for children: Use of the common assessment framework.

Citation: *Journal of Interprofessional Care*, Mar 2012, vol. 26, no. 2, p. 134-140, 1356-1820 (March 2012)

Author(s): Collins, Fiona, McCray, Janet

Abstract: Transformation in the structure and delivery of services for children and young people in the UK Children Act (Department for Education & Skills, 2004. *The Children Act*. London: HMSO) initiated new alliances between statutory, public and voluntary agencies. Traditional relationships and notions of partnership have been extended, necessitating an

innovative approach to dialogue and multiple perspectives. Hudson's assertion that although the "rhetoric on partnering remains strong, the real policy thrust is now about choice and contestability" (2006, *Journal of Integrated Care*, 14(1), 13-21) exemplifies the dynamic policy context around notions of partnership and the rationale for collaborative advantage. This paper explores the experiences of practitioners working in a relatively new multi-agency context - the common assessment framework (CAF). Envisaged as a standardized approach to the assessment of need and as a tool to facilitate integrated working, the CAF is utilized by practitioners in the UK to improve outcomes for children and young people. We present data from a study that employed an interpretative phenomenological analysis approach and gathered semi-structured interviews with 20 practitioners. Interviews drew upon their experiences of interprofessional working in which diversity, partnership working, and competing aims and objectives emerged as significant themes. The insights that were gained are discussed in terms of their potential impact on service delivery in the UK and their contribution toward responsive practice across dynamic professional boundaries.
[PUBLICATION]

Full text available from EBSCO host in *Journal of Interprofessional Care*

Title: Needs of families with children who have a physical disability: a literature review.

Citation: *Critical Reviews in Physical & Rehabilitation Medicine*, 01 January 2012, vol./is. 24/1-2(85-108), 08962960

Author(s): Siebes, Renate C, Ketelaar, Marjolijn, Gorter, Jan Willem, Alsem, Mattijs, Jongmans, Marian J

Abstract: Families of children with a physical disability experience a large variety of needs over and above those of families with typically developing children. This study reports the results of a review of the published literature on family needs. A systematic search was conducted in the ERIC, PsycINFO, and PubMed databases from their date of release until December 2011. In addition, reference lists of the assembled articles were examined for relevant literature. Articles were evaluated on study characteristics and family needs; 1823 unique abstracts were screened for eligibility, revealing 69 potentially relevant articles, of which 64 could be retrieved. Analyses of a final selection of 29 articles resulted in a list of 604 family needs (range of 1-36 needs per article), which were clustered and rephrased into 99 unique needs and organized into 14 domains. The results of the review emphasize the variety of needs that these families experience, with "information needs" taking an important place. Our findings may serve as a resource for researchers who are working to develop valid tools to assess needs of families with children with disabilities, and such a tool can be instrumental in tuning the care processes to the individual needs of these families.

Title: Respite care needs for families of children with life-limiting conditions

Citation: *Nursing children and young people*, July 2011, vol./is. 23/6(14-18), 2046-2336 (Jul 2011)

Author(s): Bowman J., Butcher R., Dolby S.

Abstract: The Framework for Respite in Partnership with Parents (FRiPP), developed by the Jessie May Trust is a tool to enable a standardised and equitable allocation of a limited resource. FRiPP reduces the opportunity for subjective allocation of respite-based care stemming from the professional-led model of telling families what they need. The tool is aimed at engaging families in identifying and articulating the support they require. After a successful pilot and evaluation, FRiPP is now used for all families on the Jessie May Trust's caseload. The authors reflect on the tool's development and implementation process in the context of promoting and protecting partnership working.

Full text: available from EBSCOhost in Nursing Children and Young People

Title: Disease trajectories and ACT/RCPCH categories in paediatric palliative care

Citation: Palliative Medicine, December 2010, vol./is. 24/8(796-806), 0269-2163 (December 2010)

Author(s): Wood F., Simpson S., Barnes E., Hain R.

Abstract: The objective of this study was to provide a preliminary description of trajectories of life-limiting conditions (LLCs) using qualitative experiential data. Semi-structured interviews were conducted with families of children with LLCs, selected to encompass all Association for Children's Palliative Care (ACT)/Royal College of Paediatrics and Child Health (RCPCH) categories, using a schedule developed from focus groups of professionals. Thirty out of 76 families agreed to participate. Four of these were unsuitable. In nine out of 26 families, their child had died. In eight out of the 26, two individuals were interviewed. Twenty-four mothers, nine fathers, one sibling and two foster-carers were interviewed in total. The interview schedule was developed from data from four themed focus groups, comprising 25 professionals from 14 backgrounds. Thirty-four milestones in five phases were identified: Diagnosis, Loss of normality, Adjusting to new normality, Palliative phase and Death. Many milestones were common to all categories, suggesting that the ACT/RCPCH system encompasses related conditions. Others occurred in only some, suggesting trajectories in the categories are distinct. Significant themes emerging from qualitative data were: becoming expert in their child, concerns about service provision, information needs and relationships with health professionals. By presenting qualitative descriptive data regarding the lived experience of families of children with LLCs, this study provides preliminary evidence that the ACT/RCPCH categories are suitable tools for research and service development. 2010 The Author(s).

Full text available from ProQuest in Palliative Medicine

Title: A new tool for assessing the needs of children with siblings requiring palliative care: The content validity study

Citation: Psycho-Oncology, May 2010, vol./is. 19/(S297-S298), 1057-9249 (May 2010)

Author(s): D'Avignon M.O., Dumont S.

Abstract: OBJECTIVES: All family members are involved in many ways in the care of a child facing a life-threatening illness, such as cancer. Siblings experience a variety of feelings and

therefore have varied needs. A new tool, which specifically assesses siblings' needs within the palliative care context is currently being systematically developed and validated. The first step of this research program is going to be presented. More specifically, item selection and content validity procedures will be described. **METHOD:** A sibling-needs typology has been developed from a qualitative study among focus groups whereby siblings and their parents were assessed separately. A pool of 135 items has been generated from this 43 needs typology, which was then subdivided in 10 domains. Four categories of experts (psychometricians, researchers, clinicians and siblings), recruited through snowball procedure, were involved in validity procedure based on the criteria of relevance and clarity. Missing needs were also identified. **RESULTS:** Content-validity study recruited 21 experts. Quantification of content validity was performed with Content-Validity Index (CVI). 38 items from the initial pool reached criterion of 0.80 CVI (28%). CVI gives a proportion of agreement between experts on item relevance and on item clarity. Eight items were deleted because they bring discomfort or redundancy. Experts identified 12 missing siblings needs. This content validity study has allowed selection of 48 items, which were included in the first version. **CONCLUSIONS:** Item selection and expert opinion are relevant aspects of tool development. A panel of experts provides constructive feedback about the quality of the newly developed measure and represents an objective criterion with which to evaluate each item. Qualitative approach underlying the need-typology and content experts will improve the instrument by a mixed-method. Indeed, siblings are actively implicated in this instrument development study. They are judged expert at the same level as clinicians or researchers.

Full text available from EBSCO host in Psycho-Oncology

Title: Bereavement needs assessment in specialist palliative care: a review literature

Citation: Palliative Medicine, 2010, vol./is. 24/1, 0269-2163

Author(s): Agnew, A, Manktelow, R, Taylor, BJ, Jones, L

Abstract: Bereavement needs assessment for specialist palliative care services has been highlighted as important by NICE guidance on palliative care for adults with cancer. Identifying and implementing appropriate bereavement measurement tools has remained a challenge. This paper identifies and reviews bereavement measurement tools to determine their suitability for use within bereavement services and hospice settings. Cochrane, MEDLINE, PsycINFO and CINAHL, electronic databases were searched, yielding 486 papers. From fifty-nine full text papers appraised, 10 measurement tools were analysed in detail. Some tools had been tested on specific populations which limited transferability to specialist palliative care settings; some lacked adequate theoretical links and were not effective in discriminating between normal and complicated grief reactions; and some lacked clear evidence of validity or reliability. Based on these criteria, conclusions are drawn about the suitability of particular tools for UK bereavement services and hospice settings where intervention is delivered by both trained professionals and volunteers. [Journal abstract]

Full text available from EBSCO host in Palliative Medicine

Title: Framework launched to support patients with severe disabilities.

Citation: Paediatric Nursing, 01 May 2010, vol./is. 22/4(5-5), 09629513

Full text available from EBSCO host in Paediatric Nursing

Title: The assessment of resilience and vulnerability in families.

Citation: Foundation of Nursing Studies Dissemination Series, Jan 2010, vol. 5, no. 9, p. 1-4, 1478-4106 (2010)

Author(s): Bennett, H, Hopper, L

Abstract: Research at Naomi House Children's Hospice in Hampshire to develop and introduce an assessment framework for use by the Family Support Team to identify families most in need of bereavement support. Evaluation of the need for assessment and the identification, modification and pilot of a suitable tool are described and the use of an action learning group is highlighted. [(BNI unique abstract)] 8 references

Source: BNI

Title: Development and psychometric properties of the Family Life Interview.

Citation: Journal of Applied Research in Intellectual Disabilities, Jan 2010, vol. 23, no. 1, p. 52-62, 1360-2322 (January 2010)

Author(s): Llewellyn, G, Bundy, A, Mayes, R

Abstract: Research to develop and psychometrically test the Family Life Interview, a tool for assessing how well everyday family routines can be maintained by families containing a child with physical or learning disabilities. Rasch analysis was used to establish the validity, internal consistency and test-retest reliability of the tool and its usefulness for predicting out-of-home placements. [(BNI unique abstract)] 38 references

Source: BNI

Title: Bristol's framework for success.

Citation: Community Care (Sutton), Jul 2009, no. 1778, p. 20-21, 0307-5508 (July 9, 2009)

Author(s): Salari, N

Abstract: How the common assessment framework (CAF) has been successfully used by professionals in Bristol to support vulnerable children and their families. The multi-agency group training and the live eCAF system are described and their benefits are highlighted. [(BNI unique abstract)] 0 references

Available from EBSCO host in Community Care

Title: Measuring hospice services.

Citation: Paediatric Nursing, Dec 2008, vol. 20, no. 10, p. 20., 0962-9513 (December 2008)

Author(s): Gould, I

Abstract: The use of the quality tool, 'Are we getting it right?' (2004) from the Association of Children's Hospices, in undertaking a quality assessment of Claire House Children's Hospice, Wirral. [(BNI unique abstract)] 5 references

Full text available from EBSCO host in Paediatric Nursing

Title: The Support Intensity Scale.

Citation: Exceptional Parent, 01 December 2008, vol./is. 38/12(24-24), 00469157

Author(s): Apel L

Abstract: A new tool available from the American Association of Intellectual and Development Disabilities for assessing the needs of those with intellectual disabilities.

Full text available from EBSCO host in Exceptional Parent

Title: Caseload management in community children's nursing.

Citation: Paediatric Nursing, 01 April 2008, vol./is. 20/3(18-22), 09629513

Author(s): Lewis M, Pontin D

Abstract: AIM: Little is known about the working practices of community children's nurses and how they manage the complexities of working with children and young people with life-limiting, life-threatening and chronic ill-health conditions and their families. This action research project aimed to find ways of managing community children's nursing caseloads that would improve the efficiency, effectiveness and equity of services and inform negotiations with service commissioners. METHODS: A data collection template comprising six input categories was adapted from the Cornwall Community Trust's health visitor weighting framework to reflect the complexity of need and the family focus of the service provided. Data were collected for one year by nurses in one integrated community children's nursing and clinical psychology service in the Southwest of England. Qualitative interviews were held with the nurses to further explore patterns identified in the input data. RESULTS: From the documentary analysis and the interviews it was possible to identify a typical ratio of client numbers in each category which allowed the nurses to be proactive in meeting children's and families' assessed needs. The numbers of clients on caseloads fluctuated over time and varied between geographical caseload areas. The type of work carried out by individual nurses varied depending on the type of contract for their locale. However, by weighting the clients in each category it was possible to arrive at a means of meaningful comparison in terms of family centred nursing. CONCLUSION: The nursing input framework supports monthly caseload monitoring by community children's nurses and informs reports to the service commissioners as part of activity monitoring data. The mechanism will be tested in comparable services in the UK to gauge its transferability.

Full text available from EBSCO host in Paediatric Nursing

Title: Needs in rare diseases during paediatric age [Spanish] Necesidades en las enfermedades raras durante la edad pediátrica

Citation: Anales del Sistema Sanitario de Navarra, 2008, vol./is. 31/SUPPL. 2(165-175), 1137-6627 (2008)

Author(s): Gaité Pindado L., García Fuentes M., González Lamuno D., Álvarez J.L.

Language: Spanish

Abstract: All rare diseases present a common set of challenges to the sufferers and their families: diagnosis, dealing with symptoms, health information, obtaining helpful medical care, availability of medications, disability and emotional impact. Children with rare disorders are an important population from health care services, and social services perspectives, and families are providing long-term care for these chronically ill children. The impact of rare disorders in children is far-reaching, extending beyond the child to all those with whom he/she has contact. Multiple facets of life are affected including social and family relationships, economical well-being and activities of daily living. The assessment of needs for rare disorders treatment is a critical step in providing high quality care and achieving patients' and families' satisfaction. Findings from different studies show that people with rare diseases have medical and social needs. Social needs are becoming more relevant in developed countries where health care services, even with limitations, have greater availability than social services. Furthermore, it seems that health care and social services for persons with rare diseases need to be improved to address the patients' needs and to provide better support to families. Validated tools with good psychometric properties are still needed to assess quality of care on the basis of patients and family needs.

Title: Using an assessment framework: outcomes from a pilot study.

Citation: Journal of Children's Services, Jun 2007, vol. 2, no. 1, p. 37-47, 1746-6660 (June 2007)

Author(s): Buckley, H, Whelan, S, Murphy, C

Abstract: Research into the use of an assessment framework for vulnerable children and their families in pilot areas in Ireland. Standardisation of practice, effectiveness, transparency, collaboration between disciplines and user-friendly qualities were evaluated. [(BNI unique abstract)] 43 references

Full text available from ProQuest in Journal of Children's Services

Title: Care dependency among school-aged children: literature review.

Citation: Nursing and Health Sciences, Jun 2007, vol. 9, no. 2, p. 142-149, 1441-0745 (June 2007)

Author(s): Tork, H, Lohrmann, C, Dassen, T

Abstract: Literature review on levels of care dependency among children with disability and chronic illness and factors that might influence their dependency level. 4 categories of factors associated with children's care dependency are described: demographic, socio-cultural, psychosocial and physical. Instruments available to measure care dependency are identified and discussed. [(BNI unique abstract)] 30 references

Full text available from EBSCOhost in Nursing and Health Sciences

Title: Paediatric palliative care. The potential of integrated multi-agency care pathways for children.

Citation: British Journal of Nursing, 27 July 2006, vol./is. 15/14(764-768), 09660461

Author(s): Davies R

Abstract: In 2004, a Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-Threatening and Life-Limiting Conditions, funded by the Department of Health, was developed by a working party. It included the Association for Children with Life-Threatening or Terminal Conditions and their Families, the Royal College of Nursing and the Royal College of Paediatrics and Child Health. This article will identify the need for this framework and its potential to transform the delivery of palliative care services to overcome present inequalities based on condition and geography that currently beset children with these conditions and their families. It will show how the three stages of the pathway (diagnosis or recognition, living with a condition, and end of life and bereavement) follow the patient's journey and complement guidance set out in the Children's National Service Framework (2004) for multi-agency assessments, protocols and standards to ensure high-quality coordinated care and services. It concludes with the need to evaluate the effectiveness of pathways that may develop from this initiative through audit and research.

Title: Caring for children with complex health needs.

Citation: Journal of Community Nursing, Jun 2006, vol. 20, no. 6, p. 4-14, 0263-4465 (June 2006)

Author(s): Condliffe, C

Abstract: Development of the community children's nursing service to meet the continuing care needs of children with learning disabilities and complex health needs being cared for at home. Relevant government policies are discussed and the role of the community children's nurse, in particular in needs assessment, is examined. [(BNI unique abstract)] 58 references

Available from ProQuest in Journal of Community Nursing

Title: Construct and criterion validities of the Service Need Assessment Profile (SNAP): a measure of support for people with disabilities.

Citation: Journal of Intellectual & Developmental Disability, 01 September 2006, vol./is. 31/3(148-155), 13668250

Author(s): Guscia R, Harries J, Kirby N, Nettelbeck T, Taplin J

Abstract: Background The Service Need Assessment Profile (SNAP) measures individual functional needs in areas of daily living. It produces a support profile, detailing the time allocations for staff support to assist in each area of need. The Supports Intensity Scale (SIS) is a support needs assessment scale designed to provide an objective measure of a person's need for support in medical, behavioural, and life activities. SIS can be used for individualised support planning, clinical judgements regarding support needs, resource allocation and financial planning. The Inventory for Client and Agency Planning (ICAP) assesses adaptive and maladaptive behaviours and gathers additional information to determine type and amount of special assistance that people with disabilities need., Method This study evaluated the construct and criterion validities of SNAP in relation to the SIS and ICAP, using assessment data from 114 individuals with a range of disabilities and levels of severity., Results Construct and criterion validities were supported for the SNAP by high correlations with SIS, ICAP, and staff estimates of support needs and by its capacity to discriminate between sub-groups in expected ways., Conclusions The results provide support for the use of SNAP as a support needs instrument.

Full text: Available EBSCO host at Journal of Intellectual and Developmental Disability

Title: Predicting family adjustment and parenting stress in childhood disability services using brief assessment tools.

Citation: Journal of Intellectual & Developmental Disability, 01 December 2005, vol./is. 30/4(217-225), 13668250

Author(s): Trute B, Hiebert-Murphy D

Abstract: Background The utility of two 'psychosocial sensor measures' was explored for triage use in childhood disability services to detect households at longer-term risk for parent and family distress. Method Approximately 6 months after entering childhood disability services, mothers and fathers in 111 Canadian families with a young child with a developmental or cognitive disability identified their family service needs and parenting morale. One year later parents completed standardised measures of parenting stress and family adjustment. Results Two brief measures assessing family counselling needs and parenting morale detected longer-term family maladjustment from the independent perspectives of mothers and fathers. Although mothers' parenting stress in the longer-term was detected by the set of measures, fathers' parenting stress was only detected by their parenting morale. Conclusions Brief empirical measures with high face validity may facilitate the process of assessment of service needs, and may help in the early identification of families with higher priority for psychosocial family support resources in childhood disability services.

Full text available from EBSCO host in Journal of Intellectual and Developmental Disability

Title: Reliability of the Service Need Assessment Profile (SNAP): a measure of support for people with disabilities.

Citation: Journal of Intellectual & Developmental Disability, 01 March 2005, vol./is. 30/1(24-30), 13668250

Author(s): Guscia R, Harries J, Kirby N, Nettelbeck T, Taplin J

Abstract: Background Measures for estimating costs associated with the provision of disability services in Australia have not previously been available. Because such instruments are scarce worldwide, decisions about funding services have relied more on historical precedent and less on individual need. Recognising the necessity for an objective measure, Gould (1998) developed the Service Need Assessment Profile (SNAP), a scale for estimating the support needs and associated costs for people with disabilities., **Method** This study examined the technical properties of SNAP using assessment data from 318 adults (190 males and 128 females), mean age 43 years, with a range of disability types and levels of severity, residing in supported accommodation around metropolitan Adelaide, South Australia., **Results** Results suggest that SNAP's reliability varies across different sub-groups and across domains., **Conclusion** Using SNAP assessments as a method for allocating funds/ resources across the disability sector should be approached cautiously, bearing in mind the reported limitations.

Full text available EBSCO host at Journal of Intellectual and Developmental Disability

Title: Conceptualizing and measuring family quality of life.

Citation: Journal of Intellectual Disability Research, 01 October 2005, vol./is. 49/Part 10(777-783), 09642633

Author(s): Summers JA, Poston DJ, Turnbull AP, Marquis J, Hoffman L, Mannan H, Wang M

Abstract: **BACKGROUND:** Increasing emphasis on family-centred approaches to services and supports for families of children with disabilities has surfaced the issue of accountability for family outcomes. We present a review of literature about the impacts of children with disabilities on families as a backdrop to proposing family quality of life as a concept that encompasses impacts of disability and one that can be used to assess the impact of supports and services on families. **METHOD:** We briefly introduce the Beach Center Family Quality of Life Scale, providing information about its factor structure, reliability and convergent validity. **RESULTS:** The Beach Center Family Quality of Life Scale contains 25 items assessing family ratings of importance and satisfaction with five domains: Family interaction, Parenting, Emotional well-being, Physical/material well-being and Disability-related supports. **CONCLUSION:** We present a framework for utilizing a measure of family quality of life as a long-term outcome in concert with other short-term measures of service outcomes for families.

Full text available from EBSCO host in Journal of Intellectual Disability Research

Title: Complex care packages: supporting seamless discharge for child and family.

Citation: Paediatric Nursing, 01 September 2005, vol./is. 17/7(30-32), 09629513

Author(s): Stephens N

Abstract: Nikki Stephens discusses a framework set up to smooth the transition from hospital to home for children with complex needs which could provide a benchmark for community teams.

Full text available from EBSCO host in Paediatric Nursing

Title: Time to go home: putting together a package of care.

Citation: Child: Care, Health & Development, May 2004, vol. 30, no. 3, p. 243-247, 0305-1862 (May 2004)

Author(s): Gatford, A

Abstract: Case study illustrating the planning and co-ordination of discharge from a tertiary specialist rehabilitation centre for children with disabilities or complex health needs. The process of multidisciplinary assessment, care planning and discharge review for a child with severe brain damage following an accident shows the problems inherent in co-ordinating the health and social services required to allow the child home. Includes commentary. [(BNI unique abstract)] 14 references

Full text available from EBSCOhost in Child: Care, Health and Development

Title: Working partnerships? A critique of the process of multi-agency working in services to disabled children with complex healthcare needs.

Citation: Journal of Integrated Care, Apr 2004, vol. 12, no. 2, p. 24-34, 1476-9018 (April 2004)

Author(s): Townsley, R, Watson, D, Abbott, D

Abstract: Empirical research into the features of 6 services designed for children with complex health care needs to investigate successes and barriers within multi-agency work. Each service was evaluated for its effectiveness in co-ordinating services, care planning, assessments and reviews. [(BNI unique abstract)] 12 references

Full text available from ProQuest in Journal of Integrated Care

Title: Assessing respite provision: the Leeds nursing dependency score.

Citation: Paediatric Nursing, Mar 2004, vol. 16, no. 2, p. 27-30, 0962-9513 (March 2004)

Author(s): Escolme, D, James, C

Abstract: Development of a dependency scoring tool in Leeds which assesses the respite needs of children and their families for access to a purpose built respite unit and continuing care service. [(BNI unique abstract)] 11 references

Full text available from EBSCO host in Paediatric Nursing

Title: Development and validation of a tool to measure the impact of childhood disabilities on the lives of children and families.

Citation: Child: Care, Health & Development, Jan 2003, vol. 29, no. 1, p. 21-34, 0305-1862 (January 2003)

Author(s): Jessen, E, Colver, A, Mackie, P

Abstract: Research using the Generic Lifestyle Assessment Questionnaire to determine the impact of disability on home life. [(BNI unique abstract)] 44 references

Title: Supporting families in need.

Citation: Paediatric Nursing, Jul 2002, vol. 14, no. 6, p. 25-28, 0962-9513 (July 2002)

Author(s): Barnes, D

Abstract: Project identifying needs using an interagency assessment tool in Lincolnshire. [(BNI unique abstract)] 8 references

Full text available from EBSCOhost in Paediatric Nursing

Title: Assessing dependency in a community hospice service.

Citation: Paediatric Nursing, 01 April 2002, vol./is. 14/3(30-31), 09629513

Author(s): Conisbee E

Abstract: A dependency tool developed by a children's hospice service identifies skill-mix requirements and training needs, as Elaine Conisbee explains.

Full Text available from EBSCOhost in Paediatric Nursing

Title: Defining the family : towards a critical framework for families of children with disabilities.

Citation: Learning Disability Bulletin, 2000, vol./is. /115(6)

Author(s): Carpenter, Barry

Abstract: Family-centred approaches are widely recognised internationally as the most ecologically appropriate ways of working with families of children with disabilities. Pivotal in this approach is its focus upon the needs of the whole family, rather than only the needs of the child (with a disability). It places a significant emphasis on flexible and responsive transdisciplinary service delivery and upon parent choice and decision-making. For the family centred approach to become truly effective, then, we must define what constitutes a family. Or rather ask families how they define themselves. Alongside an exploration of traditional and non-traditional family roles, this paper challenges stereotypical notions of the

family, and seeks to establish the family as the core element in any service team. 1 fig. 31 refs. [Abstract]

Title: The lifestyle assessment questionnaire: an instrument to measure the impact of disability on the lives of children with cerebral palsy and their families.

Citation: Child: Care, Health & Development, Nov 1998, vol. 24, no. 6, p. 473-486, 0305-1862 (November 1998)

Author(s): Mackie, P, Jessen, E, Jarvis, S

Abstract: Creation of a tool to assess the impact of disability. [(BNI unique abstract)] 26 references

Title: Respite care needs met and unmet: Assessment of needs for children with disability

Citation: Developmental Medicine and Child Neurology, 1997, vol./is. 39/8(548-553), 0012-1622 (1997)

Author(s): Treneman M., Corkery A., Dowdney L., Hammond J.

Abstract: The study aimed to ascertain the current use of respite-care services by families with children with a learning and/or a physical disability in a South London, UK, health authority, to estimate the type and extent of the unmet need, and to set standards for the provision of such services. Over 1200 families were sent an 11-page questionnaire. The results indicated that the child's level of dependency and the presence of behaviour and communication problems led to significantly higher levels of experienced stress among carers. This was also associated with a significantly greater use of respite care except by families of children with behavioural problems. The results showed that respite care was generally perceived as an inadequate service, though 38% of respondents had no knowledge of the existence of respite-care services. Recommendations are made in relation to information provision, choice, and flexibility for carers and for quality standards in general.

Title: Inter-agency assessment of respite care needs of families of children with special needs in Fife.

Citation: Public Health, May 1996, vol. 110, no. 3, p. 151-155, 0033-3506 (May 1996)

Author(s): Campbell, H

Title: Understanding and helping families with neurodevelopmental and neuropsychiatric special needs.

Citation: Pediatric Clinics of North America, February 1995, vol./is. 42/1(143-51), 0031-3955;0031-3955 (1995 Feb)

Author(s): Taylor EH

Abstract: Children with persistent neurodevelopmental and neuropsychiatric problems have

extensive treatment, care, and community service needs. The child's disabilities can create new responsibilities, emotions, roles, and goals for the family. This article provides a framework for identifying and categorizing children with special needs. In addition, methods for assessing the family's psychoeducational, social, and emotional concerns are presented.

Title: Focus group interview with parents of children with medically complex needs: an intimate look at their perceptions and feelings.

Citation: Children's Health Care, 1991, vol./is. 20/3(170-8), 0273-9615;0273-9615 (1991)

Author(s): Diehl SF, Moffitt KA, Wade SM

Abstract: The purpose of this paper was to identify the needs of parents of children with medically complex needs from their own perception. In order to provide in-depth information, the focus group interview technique was used. Several strong recurrent themes were identified. The most persistent need was for a general organization or framework with which the care providers could operate. Along these same lines, the fragmentation of training, needs and services was consistently stated. A general lack of information in terms of home care and how to plan for the future was identified. Support groups were universally lauded for the invaluable services provided to the care parents.

Full text available from EBSCO host in Children's Health Care

Search History

1. CINAHL; (assess* ADJ2 need*).ti,ab; 6740 results.
2. CINAHL; NEEDS ASSESSMENT/ OR HEALTH SERVICES NEEDS AND DEMAND/; 18894 results.
3. CINAHL; dependency.ti,ab; 3670 results.
4. CINAHL; score*.ti,ab; 84543 results.
5. CINAHL; tool*.ti,ab; 51063 results.
6. CINAHL; framework*.ti,ab; 30155 results.
7. CINAHL; life-limit*.ti,ab; 471 results.
8. CINAHL; "continuing care".ti,ab; 746 results.
9. CINAHL; "complex need*".ti,ab; 567 results.
10. CINAHL; disab*.ti,ab; 48718 results.
11. CINAHL; short-break*.ti,ab; 64 results.
12. CINAHL; respite.ti,ab; 916 results.

13. CINAHL; RESPITE CARE/; 992 results.
14. CINAHL; CHILD, DISABLED/; 6481 results.
15. CINAHL; hospice*.ti,ab; 7352 results.
16. CINAHL; exp HOSPICES/ OR exp HOSPICE AND PALLIATIVE NURSING/; 5116 results.
17. CINAHL; exp PALLIATIVE CARE/; 16863 results.
18. CINAHL; palliative.ti,ab; 14197 results.
19. CINAHL; child*.ti,ab; 168971 results.
20. CINAHL; 1 OR 2; 23712 results.
21. CINAHL; 3 OR 4 OR 5 OR 6; 159654 results.
22. CINAHL; 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 15 OR 16 OR 17 OR 18; 78169 results.
23. CINAHL; 14 OR 19; 171770 results.
24. CINAHL; 20 AND 21 AND 22 AND 23; 67 results.

In this appendix we have given some examples of allocation practice from a selection of hospices who took part in this project.

Outcomes based model

1. Acorns outcomes based assessments

Acorns offer a range of holistic services to support both the child and wider family members. Once a child has been accepted for services from Acorns an appointment is made with the parent/ carer to visit them in their home by the Acorns Community Team Worker. The community team workers are registered professionals from multi-disciplinary backgrounds and have been provided with training on outcome based assessments. The purpose of the first visit is to establish a relationship with the family and enable them to tell us their 'story'. During the first home visit and subsequent visits the community team worker will begin the assessment of the child and family's needs and offer Acorns services based on need and identified outcomes.

The psychosocial support offered by the Community Team Worker (CTW) involves a range of interventions based on the on-going assessment of family need, the CTW delivers measurable outcomes from the work undertaken to ensure the health and wellbeing of the whole family. The work includes counselling, information giving, acting as mediators and advocates, working with complex and resistant families where there may be safeguarding concerns. Workers may also involve liaison with external professionals, at the families' request, in an effort to put together a package of care or support. CTW act at the interface between the family at home, and their use of the palliative short-breaks and end of life care facilities based at the hospice or hospice at home as appropriate. The CTW is their primary contact with hospice services they take overall responsibility for all reviews which occur every 12 months or more frequently if there is a change of circumstance for the child/ family.

Acorns outcomes based model uses the fifteen outcomes which encompass every child matters and also the priorities and perceptions of disabled children and young people and their parents regarding outcomes from support services (York 2007). The premise for the model is " disabled children aspired to the same sort of outcomes as non-disabled children, However what these outcomes meant, the way they were prioritised, and the level of achievement expected, often differed from non-disabled children" The aim of the model is to work to the families' desired outcomes for service intervention. The family is able to provide their views which are presented as their outcomes. (Patient participation is seen as key in assessment; NICE guidance 2005 , Ueda et al ;2013) The worker would also then relate these to the fifteen outcomes and how this then is transferable into services and intervention received. The evidence and measure of work is then reviewed on a regular basis and whether the family outcomes have been met/unmet.

Acorns is currently undertaking work to identify a data base system where all measurable outcomes can be elicited and used to provide evidence for commissioners on the impact of the work undertaken.

2. EACH Holistic Needs¹ and Outcomes based Approach

EACH offers a range of universal, targeted and specialist palliative care services. To ensure that families receive the care that they need, a new approach is currently being implemented which is based on understanding the holistic needs of the whole family and their goals and expectations of how EACH may be able to make a difference to them.

Once a family have been accepted for EACH services, a holistic needs assessment (HNA) is carried out by an EACH Care manager. The HNA aims to support our engagement with families, to identify their hopes, expectations and fears for involvement with EACH and to help us identify how EACH could make a difference to them, including their perceived needs and concerns of the whole family system. It enables us to identify those that are in greatest need and/or most immediate risk, use our resources effectively and ensures that EACH provides personalised care which reflects need.

It is conducted in a conversational style. Prompts are available relating to different domains, e.g. demographics, setting the scene, getting to know the family, relationship to help, physical needs, environment, social/family situation, educational/occupational needs, psychological well-being of the whole family and spiritual needs have been developed to help guide the conversation.

The HNA focuses on family resilience, strength and resources, incorporates a genogram, which may also map professional systems involved. It is supplemented by other measures, such as person-centred tools, the distress thermometer and the DISDAT.

The information gathered is analysed and discussed by the EACH locality multi-disciplinary panel. If a need for a targeted intervention has been identified (short break, enhanced level emotional support, hydrotherapy or symptom management) an additional assessment is completed.

Those referred for end of life care automatically receive the care they need where and when they need it. The HNA approach helps to develop a family based plan of care very quickly.

Families who are referred for reasons other than end of life care, will have an individualised plan of care agreed with them based on the findings of the assessments. Given the high demand for short breaks, if the needs of the CYP reach the threshold to enable access to short breaks, a number of sessions is agreed with the family per year based on their level of need.

The family receive a copy of a report of the HNA and further assessments and an individualised plan of care for the whole family is subsequently agreed.

The individualised offer of care and support is formally reviewed at least annually or more frequently if circumstances change. 'Touch base' customer service type contacts are made by care staff in between to families check that EACH is meeting the family's expectations and needs and that they are satisfied with the services provided.

¹ "a holistic health and social care assessment undertaken in order to identify supportive and palliative care needs of an individual and to trigger any specialist assessment that may be required" (NCAT, 2007).

3. Scoring based

Forget Me Not Children's Hospice

At Forget Me Not, we hold a referral panel once a fortnight. Our approach to acceptance and allocation has evolved over time, however continues to centre around a multi-professional panel, which includes representatives from the hospice and outside partners. This approach generates discussion around the needs of the child and family, within the context of local service provision.

We have developed a needs-based tool* for scoring children and families, recognising the impact of social factors as well as health needs of the child and other members of the family. The tool helps us to demonstrate consistency, equity and transparency in our process.

Over the last few months we have appointed a staff nurse to visit the families at home prior to acceptance to enable the scoring tool to be completed. This has reduced the time between referral and acceptance, reducing our dependence on the return of evidence from professionals, making the process less of a 'paper exercise'. The introduction of a staff nurse has also made the process more meaningful and has significantly increased the quality of the evidence submitted for consideration to the referral panel.

We offer enhanced community-based care as well as care within our hospice. Once accepted, families are allocated a number of short break (respite) nights per year (range: 8 – 12 nights) and community hours per week (range: 2 – 6 hours). In addition, we offer emergency respite, symptom control, end of life and bereavement care; which can be delivered either in the hospice or at home. Additional services are offered over and above the allocation; examples include complementary therapy, music therapy and hydrotherapy.

The full document can be viewed here

http://www.togetherforshortlives.org.uk/professionals/external_resources/4905_forget_me_not_childrens_hospice_allocation_of_care_document

4. Resource based

Northern Ireland Hospice – Reactive Model

Once a child had been accepted to the service under the specified criteria which is considered by a multidisciplinary panel they are assigned a key worker. The key worker will meet the family and describe the range of services available, this includes short stay, hospice at home, day care, use of the pool and family support. The family will then choose what aspects they feel will meet their needs at that time. The flexibility of care provision allows for families to avail of one or all of the parts of the service as they choose or as their needs change.

For short stays and day care:

An allocation meeting is held 4-monthly with the key worker for the families and the bed manager. We tailor the number of beds available across the whole period, this allows us to react to staffing or resource issues by reducing bed nights if required. A day care space is considered as one bed night.

Families are allocated their stay, taking into account requests for special occasions. The service runs one bed as an emergency bed which parents are notified of along with this allocated date and should we need to react to end of life care or any other unpredicted circumstance the child in the emergency bed will be sent home.

Advantages

- Plan ahead within resources and prevent last minute cancellations.
- Structure dependencies of children to balance dependency against skill mix.
- Plan use of specialised equipment e.g. safe space bed.
- Clearly identify opportunities for cancellation spaces.

Disadvantages

- Resource is not a definite for families.

For Hospice at Home:

Resources are generated from contractual arrangements with Health Care Trusts. This can result in services being inconsistent across the region.

Use of the pool outside of short stay:

Resourced by specifically trained volunteers for children who cannot use public facilities.

Family Support:

Compliments the work of all aspects of the service. Delivered by a Senior Social Work Practitioner, the resource is flexible to meet identified need.

5. Non- outcome based model.

Shooting Star Chase

All children referred to Shooting Star Chase are discussed at the weekly multi- professional referral and review panel and acceptance to the service communicated in writing. Children are accepted based on their condition meeting the hospice criteria for support and the families allocated 12 nights of planned short break care at the hospices, this can be converted into day care when 2 day care sessions equals one night of allocation. In addition to this children and their families can be admitted in a crisis, for end of life care or for symptom management, without this affecting their allocation for planned short breaks, funding from CCG's or social care is sought for this additional care. 'Step down care' is also provided on a funded basis or through use of allocation.

All families accepted for support, that reside in the Shooting Star Chase catchment area are assessed by a Hospice at Home Nurse and allocated a Key worker. The family can choose to use Hospice at Home support in addition to their planned short breaks at the hospice. This aspect of the service is allocated on an individual basis, but based on a guideline, detailed below. The level of support offered is discussed and agreed with the family at initial assessment and reviewed at least annually or as the child's condition or family situation changes.

A guide to the level of support to be offered by Hospice at Home is:-

Child that is pre-school age or not in education - 2 x 3 hour visits a month	Child who is less than half time in education - 1 x 3 hour visit a month
Child who is in education more than half the time - 1 x 3 hours visit every 8 weeks	Child that is cared for residentially, or is in residential education - telephone contact and crisis visits

The H@H support is subject to need, and the availability of appropriately trained staff to safely and appropriately meet the child and families' needs. The level of support is increased during times of crisis, family stress and for end of life care. Families living outside the catchment area are considered for H@H support at times of crisis, or at end of life only and this is agreed following assessment and discussion at Referral and Review Panel.