

# Are the Children's and Young People's Units Disabled Friendly? A Preliminary Inquiry

Mahnaz Ilkhani, Cath Battrick, Alan Glasper, Nikki Jarrett

## Abstract

A pilot audit using a discrete aspect of a new children's and young people nursing audit tool was undertaken within a children's outpatient department at a NHS Foundation Trust prior to a full audit of compliance to child health policy related to disability. The aspect of the audit tool pertinent to disability consists of eleven individual sections utilizing a 0-10 grading scale. The pilot results demonstrate that the Trust is making good efforts in the areas of multi-agency team work, decision-making, and assessment. However, there are some aspects of policy standards that need more careful consideration, such as communication, equipment, training, and delivery of information.

**Key words:** *disabled children, care, health policy standards, benchmarks, compliance*

## Introduction

In the NHS, providers of services and those who deliver care to disabled children, in particular those with complex needs must measure and demonstrate the effectiveness of the services they are providing (Milner et al. 1996; The children's Trust Tadworth, Every Disabled Child Matters 2011). This audit was precipitated following dialogue with a parent of a disabled child regarding the standards of inpatient care their child received whilst in hospital. An audit was planned as part of a service evaluation related to the care and welfare of families with children and young people with disabilities who use the children's ward within a NHS Foundation Trust. This paper presents the results of a pilot preliminary audit of a NHS Foundation Trust in the south of England.

## Developing the Audit Tool

The audit tool is a discrete aspect of the Association of Chief Children Nurses

(ACCN) generic health care audit tool. The Association of Chief Children's Nurses is a group of senior nurses representing children's and young people services. The Compliance Assessment Instrument for this individual audit tool was configured from a comprehensive range of policy documents:

- Aiming High for Disabled Children: Best Practice to Common Practice (DH 2009)
- Aiming High for Disabled Children: Better Support for Families (HM Treasury, DfES 2007)
- Better Care: Better Lives (DH 2008)
- Disabled Child Standard, National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs (DH 2004)

- Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs (DH 2007)

- Together from the Start-Practical Guidance for Professionals Working with Disabled Children (birth to third birthday) and Their Families (DfES, DH 2003)

- Valuing People: a new Strategy for Learning Disability for the 21st Century (DH 2001)

- Valuing People Now: a New Three-Year Strategy for People with Learning Disabilities (DH 2009)

The Disability Audit Compliance Assessment Instrument comprises of 11 individual sections reflecting all aspects of the policies related to care delivery to disabled children and their families (Table 1)

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Table 1. Sections of the Disability Audit Compliance Assessment Instrument (\* indicates sections of the audit instrument not relevant for this pilot audit)

The key workers and palliative care sections were not applicable for this pilot study due to the short duration of visits for children with disabilities within this department; therefore, this current paper considers nine sections.

Table 2. One Section of Disability Audit Tool

Care Quality Commission Prompts	Evidence
Multi-agency team working	Evidence of multidisciplinary assessment tools for children with disabilities. Score 2
	A lead has been appointed for transition. Score 2
	Multidisciplinary support team with experience of dealing with challenging behaviour available where appropriate. Score 1
	The service has procedures to manage children with disabilities whose behaviour presents challenges. Score 1
	Multiagency involvement in the children with disabilities transition to adult services strategy. Score 1
	Evidence of co-ordination between the relevant agencies to transition children with disabilities to adult services with a formal health care plan. Score 2
	A family forum has been established (community setting).Score 1
<b>Total</b>	

1. Communication
2. Training
3. Multi-agency team work
4. Information
5. Support services
6. Decision making
7. Key workers\*
8. Assessments
9. Equipment
10. Palliative care \*
11. Bereavement

N.B. key informants providing evidence to complete the audit may award themselves benchmark scores of less than 1(e.g. 0.5). Maximum scores of up to 4 are achievable for some sections.

#### Aim

The aim of this pilot audit was to identify areas of optimum and less than optimum compliance to best practice benchmarks relating to the care delivery for disabled children and young people with complex health needs and their families within a children’s outpatient department.

#### Process and Methodology

Approval for the audit exercise was given by the clinical governance department of the children’s division of the hospital (in the North America, outpatient departments are referred to as ambulatory care units). Arrangements were made with the Matron to visit the children’s outpatient department and to complete the benchmarking exercise over one day. The evidence for the audit comprised observation of the unit, verbal information from staff and

written information. This was collected, documented, and verified in terms of the range of areas scored against the best practice benchmarks. Rawlins and Hine (2002) suggest that Bar charts are the most common format for audit presentation. The findings are presented here with Bar charts generated using a proprietary data analysis package.

#### Summary and Discussion of Results

##### 1. Communication (score range 0-10)

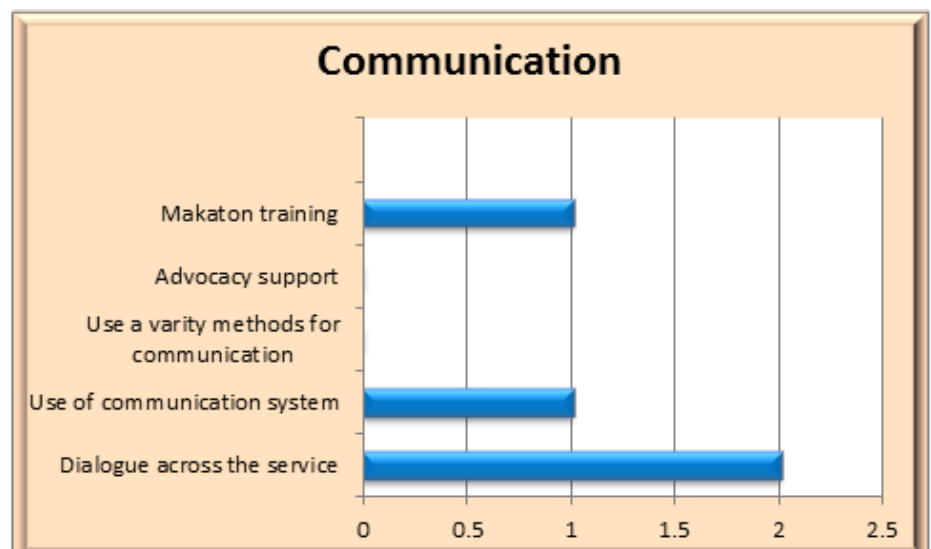


Figure 1. Evidence scores for communication

In this element of the audit, staff were questioned on a range of evidence criteria related to communication.

The White paper 'Valuing People Now: a new three year strategy for people with intellectual disabilities' (DH 2009) provides a benchmark for avoiding discrimination in minority ethnic communities with learning disabilities. This pilot audit suggests there is a lack of advocacy support for minority ethnic communities across the children's outpatient department (Figure 1). However, the dialogue related to children with disabilities across the service provision met the criteria satisfactorily. Wall mounted posters, related to children with disabilities were used around the children's outpatient department. There was tangible evidence of the development of appropriate communication systems for children with little or no verbal communication. However, the main method of communication was based on the verbal mode. Reichle & Sigafoos (1991) and Charlop and Haymes (1994) support the use of alternative interventions, such as sign language, picture-point systems, and electronic devices to assist disabled children to increase their speech ability and communication skills (Durand & Carr 1991). The importance of developing and using appropriate communication systems where people have little or no verbal communication is emphasised by the policies "The Aiming High for Disabled Children: Better Support for Families" policy (HM Treasury, DfES 2007), The White Paper 'Valuing People Now: A New three year strategy for people with intellectual disabilities' (DH 2009).

Emerson & Baines (2010) highlight that limited communication skills among health professionals may reduce the capability of staff to effectively identify the health needs of people with disabilities. Within this pilot audit, only a small number of staff were aware of Makaton, which is a language programme designed for individuals who cannot communicate efficiently by speaking (Beukelman and Mirenda, 2005). Therefore, the NHS Foundation Trust needs to review how to develop nursing skills in terms of communication with disabled children who have not developed speech.

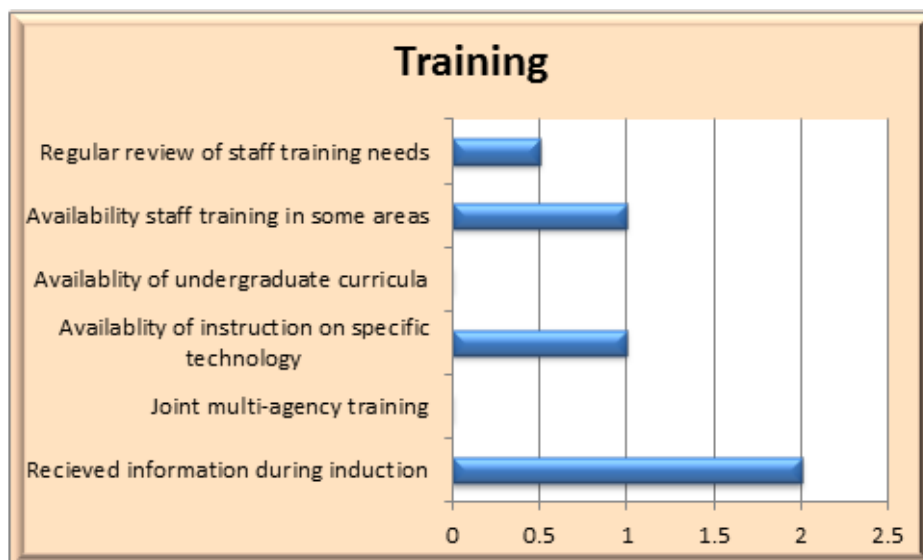


Figure 2. Evidence scores for training

## 2. Training (score range 0-10)

In this element of the pilot audit, staff were questioned on a range of evidence criteria pertinent to training (Figure 2).

The children's outpatient department of the NHS Foundation Trust does not have, as is best practice, a joint multi-agency training initiative between health, education and social services. However, there was evidence of customer care training related to the care of children with autism, and the use of experts to communicate with disabled children during some procedures, such as blood tests. The White Paper 'Valuing People Now: A New three year strategy for people with intellectual disabilities' (DH 2009) emphasises the importance of joint planning and working together. Watson et al. (2002) suggests that joined-up approaches for professionals have a positive impact on the support needs of disabled children and their families, facilitates the liaison and coordination between different service providers (Abbott et al. 2005), and improves the skills of health staff relative to care delivery to disabled children (Banks & Kane 2004). The joint agency training of staff did not meet the benchmarked criteria and therefore, the Trust post audit action plans will need to address this deficiency.

The Disabled Child Standard, National Service Framework (DH 2004) states that

children with learning disabilities have higher levels of unmet needs than their healthy counterparts; therefore, some of them require more nursing support. Additionally, the White Paper "Valuing People: A New Strategy for Learning Disability for the 21st Century" (DH 2009) emphasis the importance of health care professionals having competent skills and being well-trained in working with people with learning disabilities.

The provision of staff training across the department in some areas, such as communication and management of challenging behaviour, did not meet many of the benchmarked criteria. However, there is good evidence that, during induction, newly qualified nurses receive sufficient information related to care of disabled children.

## 3. Multi-Agency Team Work (score range 0-10)

This aspect of the audit seeks to ascertain whether multi-agency team work was established throughout the children's wards of the NHS Foundation Trust. Although the standard for multi-agency team work judged by the audit tool is generally satisfactory throughout the outpatient children's department, there are a number of issues which compromise the achievement of best practice, including: dealing with disabled children who have challenging behaviour

in terms of multidisciplinary assessment tools, support teams and availability of procedures to manage multi-agency work (Figure 3). The British Department of Health (DH 2007 ) suggests that all staff within service provision need to understand the causes of challenging behaviour. This is reinforced in the White Paper ‘Valuing People: A New Strategy for Learning Disability for the 21st Century’(DH 2001).

Collins (2008) highlights that the transitions agenda is a prominent issue throughout the White Paper “Valuing People: A New Strategy for Learning Disability for the 21st Century”(DH 2001). Additionally, the “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) emphasises that a smooth transition for disabled children to adulthood results in decreasing insecurity, increasing awareness of available opportunities, and overcoming barriers, as well as giving an opportunity to parents with disabled children to express their perspective on the services they receive. The provision of the transition service across the department satisfactorily meets the criteria as judged by the audit tool.

In addition, in order to optimise the potential of disabled young people, the Disabled Child Standard, National Service Framework (DH 2004) makes strong recommendations for improving service provision for disabled children and their families, as well as meeting their wishes

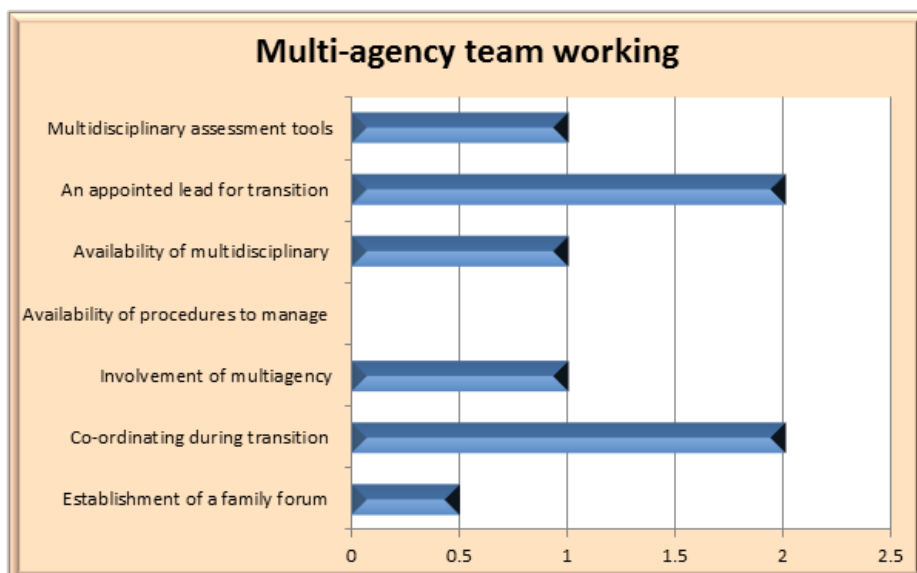


Figure 3 Evidence scores for multi-agency team work

and aspirations. The “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) provides a benchmark for family forums as an opportunity to gain awareness of the perspective of parents with disabled children related to service provision. The current pilot audit revealed that the family forum has still not been fully established across the children’s outpatient department. There is, however, good evidence of feedback from families.

#### 4. Information (score range 0-10)

This part of the audit seeks information about care delivery to disabled children

and their families within the children’s wards of the NHS Foundation Trust

The White Paper “Valuing People: A New Strategy for Learning Disability for the 21st Century” (DH 2001) emphasises the importance of giving culturally and age appropriate information to disabled children and their families in a sensitive, timely and skillful manner as a part of high quality care standards. Additionally, “Together from the Start-Practical Guidance” (DfES,DH 2003) states that parents have a right to access comprehensive, accurate and relevant information about their children and their service provision. The provision of culturally appropriate information in multimedia formats for families and their children with disabilities falls short of best practice guidelines across the department (Figure 4).

The “Better Care: Better Lives” policy (DH 2008) suggested that the process of transition should be age and developmentally appropriate, planned early and frequently reviewed. The transition pack and the information given to families within the outpatient department satisfactorily met the standards. There is good evidence of a transition plan package between paediatric and adult services within this area.

The issue of fully instructed family carers was generally non complaint to the Carers Act 2007 and the White Paper “Valuing People: A New Strategy for

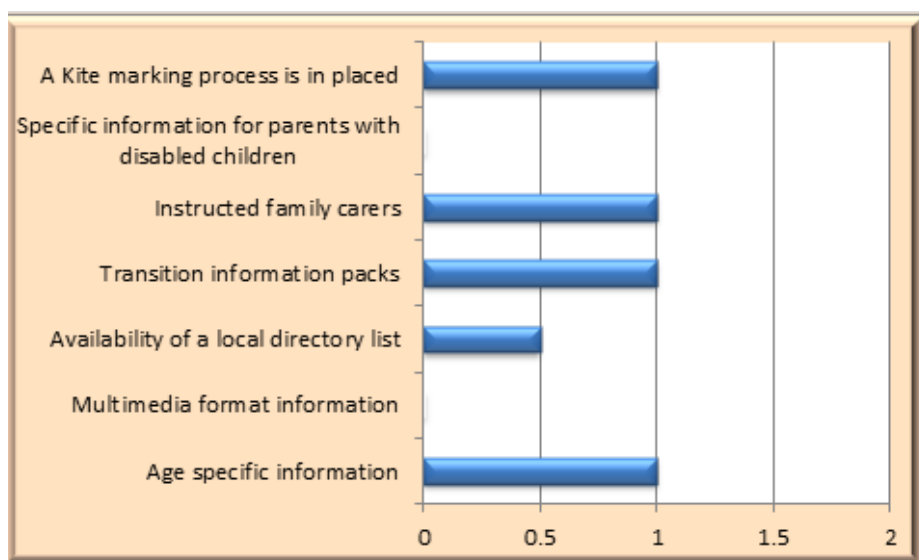


Figure 4 Evidence scores for information

Learning Disability for the 21st Century” (DH 2001). The White Paper (DH 2009) which highlighted the importance of supporting and meeting carers’ needs and providing training resources for them (Collins 2008). However, a booklet for the carers service was available within the outpatient department.

### 5. Support Services (score range 0-10)

This aspect of the audit examines the availability of support services for children with disabilities and their families.

The highest concern within this section of the pilot audit was related to the lack of access to free parking (figure 5). Clarke (2006) reported that lack of disability services such as parking is a barrier for families to access mainstream facilities and might socially exclude disabled children and their families. Additionally, access to a blue parking badge for families of children with disabilities as a facility is addressed by “Together from the Start - Practical Guidance” (DfES, DH 2003).

The standard 8 within the “Getting the Right Start Framework” (DH 2003) highly recommends that disabled children and young people should receive coordinated, high quality family-centred care based on their assessed needs. The availability of family support services appears not to be fully embedded within practice in the outpatient department. However, there are good examples of an information booklet related to family support services available throughout the Trust.

The “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) proposes short breaks to give families respite from caring and give them a normal life(Langer et al. 2010), help improve relationships between parents(Stalker & Robinson 1994), decrease parents’ stress (Cowen & Reed 2002), and provide new experiences of relationships, environments, and social activities for disabled children (Benson & Dewey 2008; Robertson et al. 2010). Short breaks may also help to prevent hospital readmission and therefore provide financial benefits for the NHS (Social Care Institute of Excellence 2008). The current pilot audit revealed that this standard needs to be raised further as at present the coordination of respite services is inadequate.

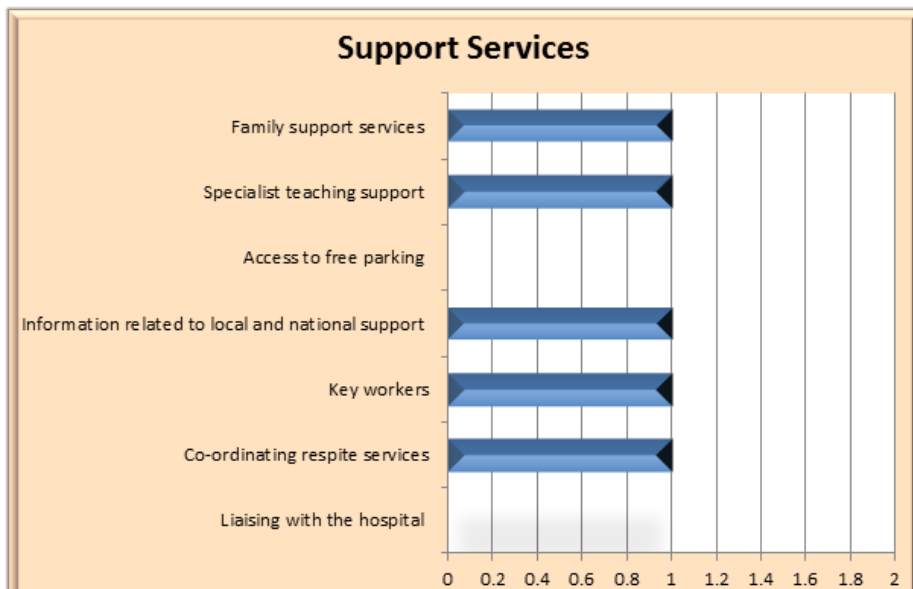


Figure 5 Evidence scores for support services

The sections related to the hospital liaising with and contributing to the Primary Care Trust early support programme was not applicable for this department.

### 6. Decision Making (score range 0-10)

This element of the audit concentrated on the extent to which children with disabilities and their families are involved with decision making related to their treatment and care.

A person-centred approach for people with learning disabilities is at the heart of the White Paper “Valuing People: A New Strategy for Learning Disability for the

21st Century”(DH 2001) (DH, 2001) which highlights that people with learning disabilities should be completely and actively involved in all decisions which impact on their lives. Additionally, the “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) argues that the shaping of services by disabled children and young people and their parents improves the outcomes of care and meeting their needs. This current pilot audit revealed that the involvement of children with disabilities and their families in decision-making is generally at a low level of development (Figure 6). The person-centered philosophy addressed by the White Paper “Valuing People: A New Strategy for Learning

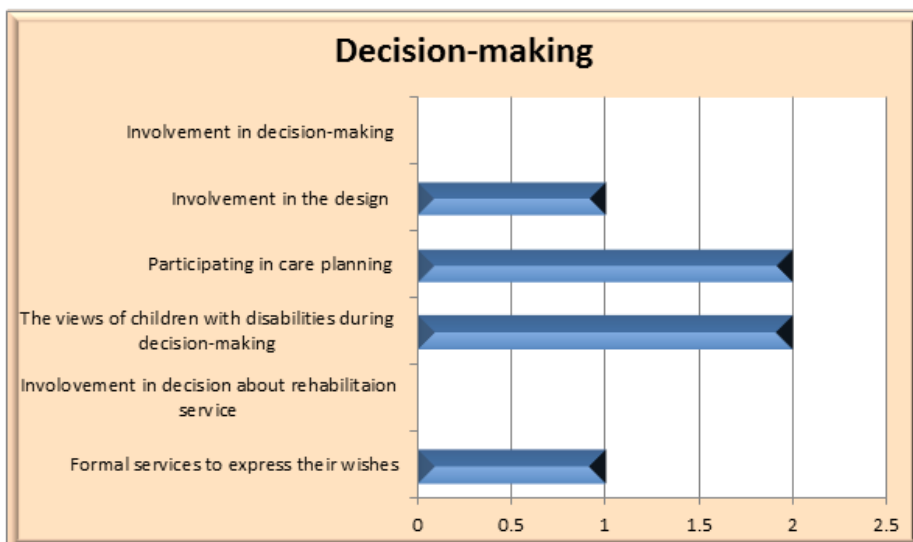


Figure 6. Evidence scores for decision making



Disability for the 21st Century” (DH 2001) and “Together From the Start-Practical Guidance for professionals working with disabled children” (DfES, DH 2003) suggests that professionals should be working in partnership with families and disabled children and involving them in any decision-making process that impacts on their provision of support. The views of children with disabilities were taken into account during every decision-making process throughout the department; thus, this segment met the required standards.

### 7. Assessments (score range 0-10)

This part of the audit seeks to investigate how multidisciplinary teams collaborate to utilize and record the common assessment framework. Accessibility to mental health services for disabled children is not investigated in the audit tool.

Multidisciplinary assessment and multidisciplinary common report fail to meet the minimum standards stipulated within the “Disabled Child Standard, National Service Framework” (DH, 2004), and the “Best Value Review Report” which suggest that children and young people with a disability and their families should be involved throughout the assessment and planning of care (Peterborough City Council 2005). The Guideline “Carer’s Assessment” is available via the NHS choices Website. However, the common record for all professional better to be considered by the Trust which could help

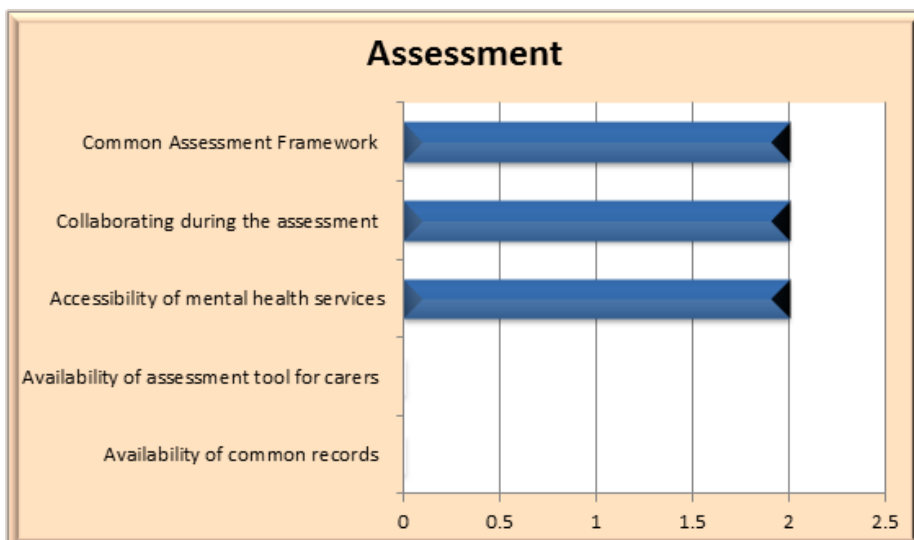


Figure 7. Evidence scores for Assessments

to enhance care delivery to disabled children.

A major concern of the White Paper “Every Child Matters: Change for Children” (2006) relates to improving working together and information sharing which lead to improved outcomes for children and their families (DfES, 2004). Therefore, this White Paper proposed the Common Assessment Form (CAF) to reduce the number and duration of different assessment processes, enhance the quality and consistency of referrals between agencies, and promote the appropriate sharing of information. The audited department generally demon-

strated good compliance with the Common Assessment Form, collaboration between all the professionals during the assessment process, and accessibility to mental health services (Figure 7).

Walsh (1998) believes that multidisciplinary record-keeping can lead to an improvement in the quality of documentation and interdisciplinary communication. The issue of common records across the Trust falls short of best practice guidelines.

### 8. Equipment (score range 0-10)

This component of the audit seeks to ascertain whether children with disabilities can access appropriate equipment and how the equipment was accessed.

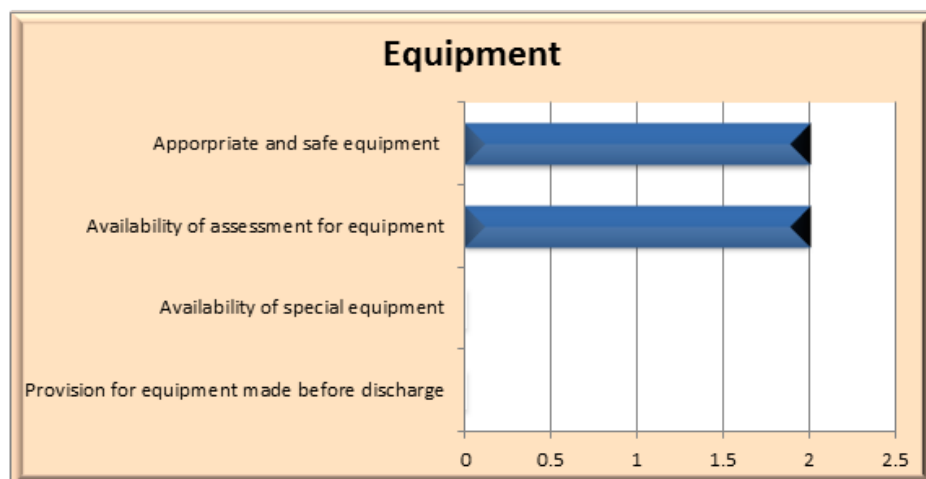


Figure 8. Evidence scores for equipment

The “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) focuses on the assessment and provision of equipment and wheelchair services for disabled children which might help to improve the efficiency of service provision and decrease waiting times. Within this audit, the lack of access to special equipment and provision of equipment before discharge across the children’s outpatient department were clearly tangible. The audit shows that only one wheelchair is available for disabled children throughout the Trust (figure 8).

There are some encouraging examples of

good practice related to appropriate, safe and age-specific equipment for children with disabilities, and the assessment for technology, equipment or wheelchair support.

### 9. Bereavement (score range 0-10)

This part of the audit examined bereavement support for families of disabled children. The “Better Care: Better Lives” best practice Guidance (DH 2008) places well-managed and well-supported end-of-life care as a key component of palliative care services. The areas of psychological, spiritual and bereavement support to disabled children and their families meet the required standards across the children’s outpatient department. A booklet related to bereavement care services was accessible throughout the Trust. Conversely, maintaining contact with families following bereavement requires further attention (Figure 9). Contact with families is a part of delivering a high standard of care to disabled children and their families.

NB: the “Care of bereaved children and young people and the effect on families of children in the end of life care plan” segments were not applicable for the department participating in the pilot audit.

#### Limitations

According to Crossan et al. (2004) and Irvine & Irvine (1991) the main point of an audit is identifying the need for changes. The biggest challenge pertaining to this pilot audit was that the auditor was not able to complete the audit cycle which is emphasised by (Sealey 1999), although the auditor prepared and submitted a report with detailed data analysis to the Trust. The Trust senior clinicians will be able to address the problems identified as part of their long term plans for improving facilities for disabled children and those with complex health needs.

#### Conclusion

A pilot audit was undertaken within a children’s outpatient department prior to a full audit of compliance to disability benchmarks of care.

The pilot audit has shown that the audit tool is sensitive enough to gather data

on disabled provision in children’s wards. The audit sections on communication, training, equipment and bereavement are generally poor and fail to meet minimum standards (Figure 10). Some fields, such as multi-agency support services, decision-making and assessments require improvement. The children’s outpatient department generally performed well. In order to meet the needs of disabled children and their families whilst in hospital, improving the areas found to be lacking or poor in the pilot audit is recommended. As this audit was only based on the Audit Compliance Assessment Instrument which takes evidence from staff, further studies on

the perspectives of children with disabilities and their families need to be planned in the future. The results of the full audit of compliance to childhood disabilities policy will be presented in a subsequent paper.

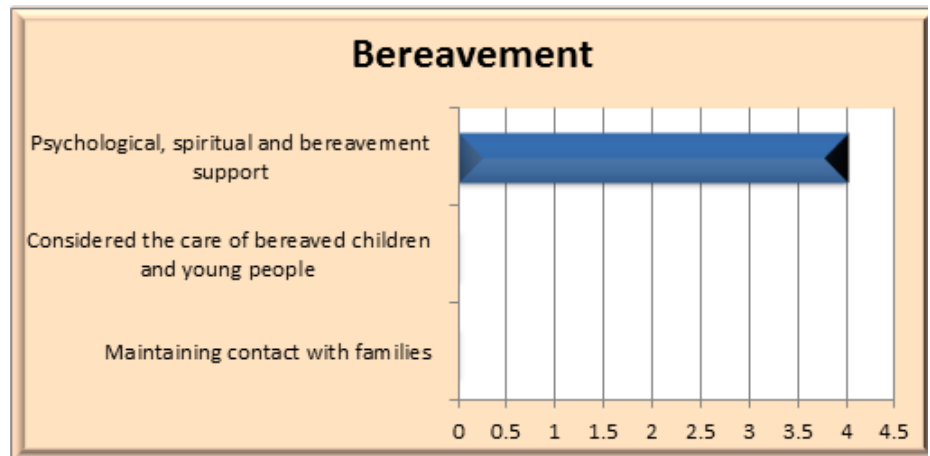


Figure 9 Evidence scores for bereavement

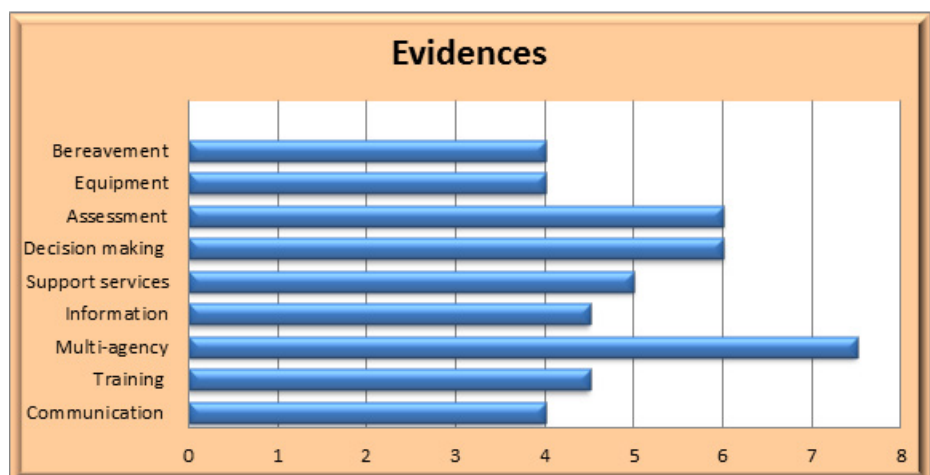


Figure 10 Comparison of the total scores among different sections (possible score range 0-10)

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