



The **Regulation** and
Quality Improvement
Authority

The Regulation and Quality Improvement Authority

An Independent Review of actions taken in response to the Health and Social Care Board report Respite Support (December 2010) and of the development of future Respite Care/Short Break Provision in Northern Ireland

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Assurance, Challenge and Improvement in Health and Social Care

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The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland.

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1. Introduction and Background to the Review

In July 2009, the Deputy Secretary of the Department of Health and Social Services and Public Safety (DHSSPS) wrote to the Director of Performance Management and Service Improvement Directorate (PMSID) at the Health and Social Board (HSC Board), seeking the assistance of the HSC Board in developing a better understanding of respite support activity across the five HSC trusts in Northern Ireland (NI).

Respite care services are aimed mainly at carers to allow them to take a break from their caring responsibilities. These services are sometimes also known as replacement care or short breaks. Carers can be informal carers who provide unpaid care to friends or relatives.

In particular, the DHSSPS sought monitoring information following the allocation of additional funding to enhance respite provision in adult learning disability and physical/sensory disability services.

Specifically, the DHSSPS requested information on:

- total expenditure on respite support in each HSC trust
- details of the organisations that trusts sub-contract with to provide respite care
- the number of places bought
- details of the type and range of respite services provided by each trust (including services provided by trusts themselves)
- an estimation of the amount of unmet need

The HSC Board agreed to undertake this work and a Performance Management and Service Improvement (PMSI) team was identified and began working in partnership with trusts.

Interim HSC Board Report (December 2009)

In December 2009, the HSC Board produced an interim report¹ which was submitted to the DHSSPS.

The HSC Board's interim report established that inadequate arrangements existed in all five trusts in respect of activity and finance information in relation to respite support activity. The report provided some useful initial benchmarking information but it was considered that further work was required to improve the robustness of the information.

¹ HSC Board Performance Management and Service Improvement Directorate. (December 2009) Management Information on Adult Respite Provision

The main findings from the HSC Board interim report were as follows:

- there were widely differing configurations of respite services across trusts and within trusts, particularly with regard to respite services provided to children
- there appeared to be a lack of formalised reporting mechanisms for respite services within trusts, making it difficult to adequately manage these services
- there was a lack of information in trust respite activity and financial monitoring systems. They were not configured in a way that enabled the provision and reporting of relevant and timely information. Trusts used activity estimates and financial costings in their returns in order to make up for the lack of specific actual data in the format required
- there was a lack of a common understanding of what constitutes respite care and a lack of a common currency in reporting respite activity within trusts. This highlighted the need for robust definitional guidance in this area
- there was a particular lack of activity information and financial systems in respite services outside residential and nursing home settings
- some trusts also had difficulty in identifying gross and net costs within financial respite reporting

In March 2010, arising from the need to explore these issues in more depth, the HSC Board wrote to trust Chief Executives advising them of a second phase of work aimed at: developing an improved understanding of the level of information regarding respite services currently recorded by each trust; determining the arrangements in place for collecting this information; agreeing the level of information required to meet the needs of all stakeholders; and agreeing how this could best be secured.

The terms of reference for this work were agreed as follows:

- to provide the HSC Board and the DHSSPS with accurate and timely information regarding activity and associated expenditure on respite care services
- to agree monthly reporting arrangements, leading to the beginning of regular monthly reporting (by October, 2010 if possible)
- to outline future plans for the development of respite care within the extant resource context
- to summarise how unmet need is recorded and dealt with in each trust

Second HSC Board Report (December 2010)

In order to take this work forward, two groups (adult and children's services) were formed and in December 2010, a second HSC Board report Respite Support² was produced, that contained six recommendations for improvement:

² HSC Board Performance Management and Service Improvement Directorate. (December 2010) Respite Support

HSC Board Report (December 2010) Recommendation 1

The Board should revise current definitions and guidance to reflect the work of the group and representations from Board and Departmental advisors.

HSC Board Report (December 2010) Recommendation 2

The Board should direct trusts to identify the 2011/12 financial year as the baseline financial year for the monitoring of respite care activity and expenditure across both adult and children's services (including short breaks). As a first step, the Board will seek comprehensive respite information for the month of March 2011, in conjunction with March PfA monitoring. It is recognised that short break funding for children can come from a variety of sources but the focus here is on PfA and associated additional funding.

HSC Board Report (December 2010) Recommendation 3

The HSC Board should review the current level of short break provision and funding within each trust with a view to addressing any inequity of provision over the course of the forthcoming Comprehensive Savings Review (CSR) period.

HSC Board Report (December 2010) Recommendation 4

The Board should establish a mechanism for reviewing the application of referral criteria across the five trusts. While acknowledging the critical role of professional judgement in each and every unique case, the aim will be as far as possible to standardise these processes.

HSC Board Report (December 2010) Recommendation 5

Respite care episodes must be provided on the basis of a written and signed carer's assessment and a carer support plan, the outcomes of which must be aggregated centrally for managerial purposes (NISAT for adults, UNOCINI for children).

HSC Board Report (December 2010) Recommendation 6

The Board should produce a commissioning statement of intent in order to set the future direction for the development of respite care. This statement should emphasise the need to promote more community based (as close to home as possible) and integrated (using a variety of approaches) respite support with a consequent reduction in the volume of residential and nursing home placement.

The second report contained both activity and expenditure information on HSC trust's respite care expenditure in adult and children's services in 2008/09 and 2009/10, which was collated from an information gathering template issued by the HSC Board in August 2010.

RQIA Review (November 2013)

As part of the Three Year Review Programme, RQIA was commissioned by the DHSSPS to review the actions taken by the HSC Board and the five HSC trusts, to implement the six recommendations, contained in the second HSC Board report Respite Support (December 2010).

The review would also consider the current arrangements in place to take forward developments in adult and children's respite services and plans in place to ensure the views of service users, families and carers are taken into account when planning for the future.

For the purposes of this review, respite care for **adults** was defined by the HSC Board as:

“the provision of short-term, temporary relief to those who are caring for others, it is any activity or service of limited duration designed to provide a break for a dependent person and their carer/service user from the usual routine”

For **children** the term short break is more commonly used and was defined by the HSC Board as:

“any service which allows a disabled child to have enjoyable planned experiences away from his/her primary carers and gives carers a break from their caring responsibilities”

The HSC Board confirmed that there was a move towards the use of the single terminology short breaks across adult and children's services, which is being taken forward by the HSC Board Short Break Development Group.

For consistency throughout this report, the term short break is used to cover both of these definitions.

2. Terms of Reference

The terms of reference agreed by RQIA with the DHSSPS were to:

1. Evaluate the effectiveness of actions taken, by the HSC Board and trusts, to implement the six recommendations in the HSC Board report on Respite Support (December 2010)
2. Consider the current arrangements in place to take forward developments in adult and children's respite services
3. Consider the arrangements in place to ensure the views of service users, families and carers are taken in to account when planning for the future
4. Report on the findings and outline the subsequent improvements in relation to access and quality of respite care/short break provision

3. Methodology

The methodology adopted for this review was designed to gather the views of staff responsible for the planning and commissioning of short break services, as well as staff responsible for delivering short break services across both adult and children's services.

In addition to this, views were sought from voluntary agencies and patient representative groups with a specific interest in short break provision, concerning the value of short break care and the quantity, range and quality of available short break services.

The methods used included:

1. A questionnaire designed to gather initial pre-review information was completed by the HSC Board. This was used by the review team to inform the later stages of the review process.
2. A series of information gathering interviews were held with key staff responsible for short break services, within the HSC Board and five HSC trusts. The purpose of these interviews was to explore their experiences and perspectives regarding the actions taken in response to the HSC Board report Respite Support (December 2010) and the development of future short break provision in NI. Each of the interviews used a semi-structured interview approach using a list of specific questions designed by the RQIA review team.
3. A further series of meetings was held with a range of voluntary agencies and patient representative groups in order to hear their views about the current provision of short break provision and the opportunities they are afforded to share and discuss their views with the HSC Board and the five HSC trusts. Approximately 40 agencies and groups were invited to meet with RQIA. Semi-structured interviews were held from November 2013 to January 2014 with 13 different groups.

4. Findings in Respect of the Six Recommendations

While the HSC Board report Respite Support (December 2010)³ was seen as the driver for improvement initiatives in short break services, the review team considered that the language used in it was not always clear or consistent, and some recommendations did not clearly delineate which recommendations related to adult and/or children's services.

With the exception of Recommendation 5, the HSC Board was identified as the organisation with responsibility for taking forward the actions. Two groups were formally established, namely:

- The Regional Respite Review and Implementation Group (Adult)
- The Regional Respite Review and Implementation Group (Children)

These were chaired by the former (now retired) Assistant Director of the PMSI Directorate at the HSC Board. Both groups had regional and carer representation and met several times from October 2011.

While there is evidence of several meetings having taken place to address the six recommendations from 2010, the review team did not find evidence of an initial action plan, to identify progress made against the six recommendations. The first indication of action was in May 2012, when the Director of Social Care and Children at the HSC Board, wrote to the Permanent Secretary at the DHSSPS (as an update to his letter of 4 April 2011) to provide an update on progress.

The letter detailed the establishment of two regional respite implementation groups. Reasons cited for the delay in setting action deadlines were due to difficulties in respect of information gathering, and a lack of basic understanding of the number of clients in receipt of short breaks in each trust, compared to the number of carers' assessments currently reported. The Director also highlighted a need for better information about unmet need and an intention to remind trusts of the need to ensure senior managers focus and engage in this work. An appendix to the letter however provided high level progress in respect of the six recommendations at that time.

Children's Services

The letter also advised that work in respect of children's services was being progressed under the Children's and Young Person's Strategic Partnership (CYPSP). Each trust representative had been asked to establish a local mirror group for implementation purposes.

Around September 2012, following an internal review by the HSC Board of existing groups within children's services, it was noted that there was overlap and duplication within a number of standing groups. As a result, the children's Regional Respite Review and Implementation Group (RRIG) was formally stood

³ HSC Board Performance Management and Service Improvement Directorate. (December 2010) Respite Support

down. It was agreed that the six recommendations for children were to be taken forward by the Children with Disabilities (CWD) Sub-group of the CYPSP, reflecting the role of short break provision in the continuum of care. The reporting line for the CWD Sub-group was agreed as the Children's Services Improvement Board (CSIB). It was clarified at the meeting of the review team and the HSC Board that this reporting line included the HSC Board's Director of Social Care and Children.

Adult Services

The adult RRIIG met from October 2011 until November 2012, when it was agreed to broaden both the focus of the group and its membership and terms of reference to encompass strategic direction.

While this group developed a sound framework for regional working, it appeared to have lost impetus until June 2013 when the Director of Social Care and Children at the HSC Board, wrote to trusts advising that a new regional group would be established to replace the current Adults Regional Respite Review Implementation Group (RRIIG). This new group included proposals for a wider and more strategic membership. As a result of Transforming Your Care: A review of Health and Social Care in Northern Ireland (December 2011)⁴, a reform agenda had been prioritised and the strategic challenge to the HSC Board was to support more carers and do so with a greater range of short break opportunities.

New terms of reference and a draft action plan, to embrace both the proposals from Transforming Your Care (TYC) and those that had begun to emerge from the Regional Respite Review Implementation Group (RRIIG), were developed. A new group was established, termed the Short Break Development Group.

At the outset of the review the review team was advised that there is a move towards the use of the single terminology of short breaks. The HSC Board considers that use of the term respite suggests solely the relief of a burden; whereas, the provision of short breaks conveys a positive experience and the maintenance of the caring relationship.

The HSC Board confirmed that while they are now using the term short break, an HSC Board directive in respect of the preferred terminology has not yet been issued to trusts.

Despite giving assurances that the terminology of short break is being used in commissioning statements across adult and children's services, the review team found that in the joint HSC Board and PHA Commissioning Plan 2013/14, the terminology of respite is still widely used.

From discussions with trusts, it was confirmed that there is a move towards the use of the single terminology short break across adult and children's services, driven by the Short Break Development Group. However, the use of this terminology is currently localised and is not always the preferred terminology used.

⁴ <http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf>

RQIA Recommendation 1:

The HSC Board should issue a clear directive to HSC trusts, confirming the requirement to use the terminology of short break, for both adult and children's services, with immediate effect.

The findings within this report are structured around the original six recommendations and will outline how they have been enacted; it should be recognised that the findings may relate to more than one of the terms of reference.

4.1 Revision of Definitions and Guidance

HSC Board Report (December 2010) Recommendation 1

The Board should revise current definitions and guidance to reflect the work of the Group and representations from Board and Departmental advisors.

As the two HSC Board reports in 2009 and 2010 examined respite support activity across the five HSC trusts in Northern Ireland with a specific focus on activity and financial data, Recommendation 1 was taken forward in respect of **data definitions**. The review team was provided with information outlining how this had been progressed across both adult and children's services.

Findings in Adult Services

The review team was advised that work around data definitions was already being undertaken before the publication of the 2010 report. The 2009/10 Priorities for Action⁵ (PfA) included targets for respite care within the areas of:

- **Physical/Sensory Disability:** by March 2010, there must be improved access to physical/sensory disability care by providing an additional 100 respite packages a year compared to the March 2008 total (and a further 100 by March 2011). Additional funding was allocated in respect of the PfA target and this in turn generated a monitoring requirement
- **Learning Disability:** by March 2010, improve access to learning disability care by providing an additional 100 respite packages a year compared to the March 2008 total (and a further 100 by March 2011)
- **Dementia:** provide an additional 1,200 dementia respite places by March 2010 compared to the March 2008 total (and a further 800 by March 2011)

In order to meet the PfA monitoring requirement, the PMSI Directorate developed reporting templates to capture data in respect of respite activity and expenditure in a consistent and meaningful way.

The PMSI Directorate devised a formula using a weighted costing calculation. The review team was advised that development of a formula to equate activity to cost was not an easy one, primarily because at the time there was no common currency for short break provision (hours, episodes, days). As a consequence the weighting formula could not be applied consistently across all HSC trusts.

The first HSC Board report (2009) reported on activity and expenditure information for 2008/09 and during quarter one of 2009/10, but only for provision of adult respite services.

The 2009 report was able to provide a menu of core areas in which short breaks were provided:

- Residential care

⁵ http://www.dhsspsni.gov.uk/pfa_09-10.pdf

- Nursing home care
- Domiciliary care
- Recreational/group respite
- High intensity care placement respite

Trusts felt that the pilot system of reporting data, in respect of respite activity and expenditure, and the associated costing formula could not be applied equally across all trusts.

In response, the HSC Board moved away from the weighted measure and focused on reporting of hourly activity. This did not reflect the cost or intensity of the care. At the time of this work, the mapping exercise still did not capture information on children's services.

For the purposes of capturing current respite activity, provided primarily for respite of the carer/service user, the adult RRIG agreed a set of data definitions and a currency of hours with all trusts. A letter dated May 2012 was issued from the Assistant Director, PMSI Directorate at the HSC Board, to key staff with responsibility for respite, information and performance monitoring within trusts. This formalised the reporting arrangements in respect of adult short break care services and included the agreed Short Break Care Definitions and Guidance 2012/13 (July 2012) and reporting templates.

In July 2012, a further letter was issued to trust Chief Executives requesting the submission of first quarter returns to the HSC Board by August 2012.

Trusts have been reporting information regarding all respite care (for adults) provided by trusts since April 2012.

Findings in Children's Services

In 2010 the DHSSPS had led on work around short breaks and a paper was issued through the Directors of Social Services Group outlining a definition and scope for the area of short breaks. A copy of this was shared with PMSI Directorate prior to the completion of the 2010 respite report. The current definition which is included in all contractual monitoring is:

'Short breaks form part of a continuum of services, which support disabled children and their families. Short breaks are provided to give:

- *disabled children and young people enjoyable experiences away from their primary carers, thereby contributing to their personal and social development and reducing social isolation;*
- *parents and families a necessary and valuable break from caring responsibilities.*

These include day, evening, overnight and weekend activities and can take place in the child's own home, the home of an approved carer, a residential or community setting'.

This definition applies across all groups of children, children with complex health care needs are classified as children with a disability, therefore this definition encompasses all. This definition would also include those children at end of life stage and those requiring palliative care.

Adult and Children's Services: Trust Comments

Trusts confirmed that they had received the Short Break Care Definitions and Guidance 2012/13 (July 2012). This formed the basis of both their internal data monitoring and the quarterly monitoring to the HSC Board. However, they had concerns that there remains some confusion and a lack of consistency around what, within the five core areas, is being categorised as short break provision and therefore segregated from routine service provision.

Trusts said that more work needs to be undertaken, across **both adult and children's services**, to ensure that monitoring is consistently applied, reflecting the same activities across all trusts. Trusts would welcome further direction from the HSC Board to improve consistency of reporting.

Trusts also felt that the definitions should be subject to future and regular review to ensure they remain consistent and descriptive of new short break services that are being developed, in the light of the modernisation and reform agenda outlined within Transforming Your Care.

RQIA Recommendation 2:

The HSC Board should continue to review the definitions and guidance for monitoring data, for both adult and children's short break provision, in order to ensure that these reflect the modernisation of services provided across the HSC.

4.2 Monitoring of Respite Care Activity and Expenditure

HSC Board Report (December 2010) Recommendation 2

The Board should direct Trusts to identify the 2011/12 financial year as the baseline financial year for the monitoring of respite care activity and expenditure across both adult and children's services (including short breaks). As a first step, the Board will seek comprehensive respite information for the month of March, 2011 in conjunction with March PfA monitoring. It is recognised that short break funding for children can be from a variety of sources but the focus here is on PfA and associated additional funding.

Findings in Adult Services

Recommendation 2 of the 2010 report required the HSC Board to establish the 2011/12 financial year as the baseline year for the monitoring of short break activity and expenditure. The HSC Board advised the review team that the baseline year for activity monitoring had been changed to 2012/13 for two reasons.

Firstly, there was significant discussion required about what constituted short break activity; as the definitions of this and agreement of a common currency of measurement were not clear. Agreement was reached in July 2012, and the HSC Board issued the Short Break Care Definitions and Guidance 2012/13 (July 2012) widely across HSC trusts.

Secondly, it was difficult to obtain accurate data from trusts who had to collect this data manually, due to limited functionality within current electronic information systems. The implementation of new community information systems remains at different stages in individual trusts. In response to this concern, it was necessary to have a testing period in order to ensure that activity returns from trusts were consistent and accurate. The HSC Board also conducted a reasonability check on the types of activity being reported; particularly where reports show wide variations between trusts.

The HSC Board routinely requests that trusts continue to ensure any information provided is validated appropriately. The HSC Board confirmed that information returns, which are quantified in hours, appear to be reliable and are consistent quarter on quarter.

The first full year of activity reporting has now been circulated to all trusts and to the DHSSPS.

The review team found that the baseline year monitoring information provided information on activity only and did not include any information on expenditure on short breaks. The HSC Board reported that this information is not available from trusts. For example, while trusts are able to monitor spending under a wider heading of domiciliary care, expenditure is not recorded against a specific short break service cost centre. The HSC Board is therefore unable to monitor the spending of trusts within the core areas of short break provision.

It was reported that **only** the additional funding and expenditure in relation to the original PfA funding is recorded. The review team learned that, in 2014, information on all expenditure on respite services remains unreported. The challenge for the HSC Board is to establish a system to fully track all expenditure for short break provision.

The HSC Board recognise that more work is required to establish clear and reliable financial reporting systems. Plans are in place to examine the totality of the resource and how this will be allocated to each trust and Local Commissioning Group.

In order to start recording expenditure information against short break activity, it is necessary for the HSC Board to direct trusts to introduce specific service lines with clear definitions of what these relate to. As elements of short breaks are integrated within other elements of care, this will need to be specifically drawn out.

Substantial work is required in relation to adult services to ensure progress. During interviews, the HSC Board finance representative indicated that while this work is challenging and time consuming, it was not impossible to take forward.

The HSC Board's Director and Assistant Directors agreed that the information systems in community services are not as advanced as those within acute services. This is presently being addressed by the reform and implementation of the new community information systems within trusts. The HSC Board recognises that it must work collaboratively to ensure that future information requirements are identified and accommodated within the revised community information systems.

The review team enquired about the quality of short break provision and how it is being monitored. The HSC Board explained that, at present, the quarterly monitoring returns do not contain quality indicators. Any information on quality is reliant on individual audits, for example those carried out by the Bamford Monitoring Group.⁶ The HSC Board advised that while the adult RRIG had more of an emphasis on information, the new Short Break Development Group has a greater emphasis on modernisation and development. The membership of this group includes carers who are very keen to look at the quality of short break services in the future. Further work is required in this area.

Findings in Children's Services

Children's services are prescribed by legislation and regulation and the basis for the provision of support for Children in Need is the Children Order (NI) 1995. Currently activity monitoring information for children's short break is collected on a quarterly basis. This monitors the number of individual children in receipt of short break services and the total number of hours provided. This activity information is included in the established reporting system for Delegated Statutory Functions and within Corporate Parenting reports. This information provided activity data only and did not include any information on expenditure, as this is currently not available from trusts.

⁶ <http://www.patientclientcouncil.hscni.net/bamford-monitoring-group>

The HSC Board described how short breaks fall within the continuum of family support services and funding allocations from the DHSSPS and the HSC Board are often not primary funding for short break care. Funding may also be derived from partnerships or other partners such as the Big Lottery Fund and other statutory bodies. The disaggregation of the information from core children's funding is seen as a significant task. At present, the HSC Board are unable to quantify the level of expenditure, in relation to children's short breaks, funded by allocations from the DHSSPS and the HSC Board.

The HSC Board further indicated that the work involved in this would be too costly and difficult to undertake at present. Short break provision is an integral part of family support and while the HSC Board can report expenditure on family support, it is currently not possible to separate the short break element.

In the future, expenditure monitoring is to be taken forward in children's, as in adult services.

The action plan for the Children and Young People Strategic Partnership (CYPSP) indicates a desire to develop a more strategic approach to allow them to identify the number of children with a disability in Northern Ireland. The CYPSP currently has a proposal to draw information on children with disabilities from a range of agencies. The HSC Board information team is taking this forward. This stems from a need for the HSC Board to be flexible in their planning, as every 10 years the profile of those with a disability changes. The HSC Board needs to be able to plan for the continued support for these children.

Adult and Children's Services: Trust Comments

Trusts confirmed that they are now providing activity based monitoring data to the HSC Board on a quarterly basis. This information includes the number of assessments completed and those declined, the number of carers supported and the number of hours of support provided. However, this monitoring contains no information on expenditure.

Some trusts have conducted small pieces of work examining expenditure associated with short break provision, often in response to a need to report activity in relation to additional funding, or as a consequence of the requirement to monitor expenditure under the TYC agenda. Presently, this work is being driven forward locally at individual trust level. None of this information on expenditure is returned to the HSC Board.

Trusts reported that, while information is returned to the HSC Board in a standardised electronic template, it often has to be collected manually. They further stated that limited functionality and management reporting in community information systems mean that standardised reporting on expenditure has not yet been established. Nevertheless, there is now a widely recognised need for this information and the HSC trusts expressed their hopes that systems can be developed, under direction from the HSC Board, in order to provide this in the future.

RQIA Recommendation 3:

The HSC Board should work with the trusts to ensure that robust systems are put in place to monitor expenditure, funded by allocations from the DHSSPS and the HSC Board, in relation to all short break provision across both adult and children's services by the end of March 2015.

RQIA Recommendation 4:

In relation to community information systems at trust level; the HSC Board should provide specific direction, to trusts, in respect of the management reporting requirements for activity and expenditure data for both adult and children's short break services which are funded by allocations directly from the DHSSPS and the HSC Board.

RQIA Recommendation 5:

The HSC Board must ensure that monitoring is developed further in the future, and designed to evaluate the quality of the services being provided across both adult and children's services.

4.3 Review of the Current Level of Short Break Provision

HSC Board Report (December 2010) Recommendation 3

The HSC Board should review the current level of short break provision and funding within each Trust with a view to addressing any inequity of provision over the course of the forthcoming CSR period.

Inequality of Investment across Trusts

The HSC Board advised the review team that historically there has been an inequity of short break provision across trusts; as a consequence of how their funding allocations were distributed across adult and children's services. However, there was no DHSSPS direction as to how this should be apportioned across adults and/or children's services. The trusts made their own decisions on how this money was allocated, resulting in differential funding between programmes of care, within trusts.

The HSC Board states that it is challenging to address the differential allocations historically but the HSC Board remains mindful of this. In some services e.g. the Child and Adolescent Mental Health Service (CAMHS), the HSC Board has made additional funding available to address areas where they have assessed trusts historically to have received inequitable funding.

The HSC Board also stated that this differential may be addressed by the Local Commissioning Groups (LCGs) using their locality funding. The LCGs will consult with the HSC Board before they take any such decisions.

The HSC Board recognises the inequities in the type of short break provision delivered across programmes of care in each trust. Information to support this has been collated and has been sent to regional commissioning teams to help them to establish the root cause of these differences in provision.

The review team noted that the original recommendation required the HSC Board to review the current level of short break provision and funding within each trust, with a view to addressing any inequity of provision within the forthcoming CSR period (which would have been the financial year 2011/12). This recommendation was not progressed in this timeline. This has resulted in a delay in addressing any inequities that may exist.

The limited functionality in electronic community information systems across trusts means that standardised reporting on expenditure has yet to be established. Trusts require better descriptors of the short break services they provide and the associated cost of these, in order to be able to plan short break service provision against the available funding allocated to short breaks. A further review of information systems to electronically report this data is required by the HSC Board.

The HSC Board stated that it needs to improve how current and future demand is identified. There is better engagement with carers and service users who are able to provide the HSC Board with information about current demand and availability.

Work continues on identifying the gaps in services and to define the level of short breaks required to support carers in specific situations.

The HSC Board continues to examine assessed need and to ensure that resources are available to meet this. They are also taking forward the vision contained within TYC aimed at offering different types of care arrangements with an emphasis on supporting carers.

Quantification of Unmet Need

The review team was told, by the HSC Board, that it is difficult to quantify unmet need at present. The HSC Board will continue to meet and engage with carers and service users about their opinions of the quality of service available. The HSC Board indicated it will continue to focus on the provision of appropriate services to meet assessed needs.

The review team is concerned that the lack of collation of information on unmet need and the lack of information on respite support activity e.g. in relation to increased costs of domiciliary short break provision, will create difficulties for trusts in being able to reduce reliance on institutional short break provision.

RQIA Recommendation 6:

The HSC Board must ensure that the original Recommendation 3 is enacted in full as a priority; and a process developed to monitor and address the inequities in provision of short break support.

4.4 Review of the Application of Referral Criteria

HSC Board Report (December 2010) Recommendation 4

The Board should establish a mechanism for reviewing the application of referral criteria across the five Trusts. While acknowledging the critical role of professional judgement in each and every unique case, the aim will be as far as possible to standardise these processes.

The current referral process to access a service is via completion of either the Northern Ireland Single Assessment Tool (NISAT)⁷ or Understanding the Needs of Children in Northern Ireland (UNOCINI)⁸ tool. Needs assessments are then progressed using each of these.

Findings in Adult Services

At present all trusts continue to apply the Regional Access Criteria for Domiciliary Care, DHSSPS (2008)⁹ which laid down a set of access criteria for domiciliary care for adults. Access criteria are based on the assessment of the person's needs and do not recognise the needs of the carer.

In order to bring consistency to referrals, the HSC Board developed a carer demand tool, using the HSC Carers Strategy Implementation Group. The aim of the carer demand tool was to ensure greater consistency in the identification of those carers in greatest need. The tool was designed to complement the NISAT carers' assessment.

The carer demand tool was piloted and it was planned to roll this out by March 2013 via trust mirror groups. Some trusts found the tool to be difficult and time consuming to use and implementation was halted. No regional consensus on the use of one tool was reached, resulting in each trust developing their own process.

The HSC Board reported that the Short Break Development Group will review the work already undertaken in relation to the carer demand tool and also examine another evidence-based tool, based on best practice in Scandinavia.

The HSC Board's Director of Social Care and Children advised the review team that the HSC Board would evaluate the original pilot alongside a review of other carers' demand tools; so as a decision can be reached.

Once a decision has been made, an associated plan for implementation will be developed. This issue has now been prioritised for development, followed by implementation of a further pilot scheme.

⁷ <http://www.dhsspsni.gov.uk/index/hss/ec-community-care/ec-northern-ireland-single-assessment-tool.htm>

⁸ http://www.dhsspsni.gov.uk/unocini_guidance.pdf

⁹ <http://www.dhsspsni.gov.uk/circular-eccu-2-2008-domicilliary-care-access-criteria.pdf>

Findings in Children's Services

The review team was advised that, for children, the UNOCINI model works well. It includes a section to evaluate the stress placed on the parents of the child, and allows for recognition of the needs of the carer.

Adult and Children's Services

While needs assessment uptake is improving, in both adult and children's services, the HSC Board has indicated that overall there is still a low uptake of assessments.

In the HSC Board Delegated Statutory Functions (DSF) Overview Report 2011/12 the statement was made that *'reporting of carers issues is variable throughout the DSF reports. This is worrying because identification and support of carers is one of the cornerstones of high quality care. There is a clear commitment, however, to carer support evidenced by an improvement in the number of assessments offered'*.

The Carers Strategy Implementation Group (CSIG) continues to explore the reasons for the low uptake and how they can improve this. The CSIG raised uptake by carers as a main priority for the immediate future. It was felt that without effective carer identification the rest of the carer support pathway is likely to fail. The HSC Board agreed that this will be progressed throughout 2013/14.

Adult and Children's Services: Trust Comments

For the purposes of needs assessment, trusts described that elements of the NISAT tool are used in most adult services while the UNOCINI tool is used in children's services. They indicated that the UNOCINI tool for children did take account of the needs of the entire family, however, the NISAT tool was not as effective in doing this. Trusts advised that the weakness of the NISAT tool is that it is based wholly around the needs of the service user.

It was confirmed that the adult RRIG had undertaken some work to develop a supporting tool; the carers demand tool. This tool was linked to the fair access criteria and aimed to ensure greater consistency in the identification of those carers in greatest need, or those exhibiting the early signs of stress.

When speaking with trust representatives, it became apparent that knowledge of the carers demand tool was variable and that some trusts had been more engaged with the pilot process than others.

In general, trusts considered that there is a requirement for an additional carer's assessment tool to sit alongside, or to be incorporated within, the current NISAT assessment tool for adult services.

The review team welcomed the fact that this issue has now been prioritised for development in the Short Break Development Group three year action plan.

With regard to Recommendation 4, the review team were advised by the HSC Board that this would be taken forward following implementation of standardised criteria across the region. A plan for this implementation has been outlined in the

2013-16 HSC Board action plan which states that regional standardisation of eligibility criteria for respite will be put in place, followed by a planned audit of the amended eligibility criteria. This objective will be completed in 2015-16

4.5 Provision of Respite Care Episodes on the Basis of a Carer's Assessment

HSC Board Report (December 2010) Recommendation 5

Respite care episodes must be provided on the basis of a written and signed carer's assessment and a carer support plan, the outcomes of which must be aggregated centrally for managerial purposes (NISAT for adults, UNOCINI for children).

The HSC Board informed the review team that the 2010 report was submitted to DHSSPS. After submission, it was confirmed that, there was a desire to see the direct link between carers' assessments and provision of short breaks become the norm. However, circumstances could be envisaged whereby short break provision was appropriate, even though the carer refused the offer of assessment or was not able to participate in that assessment.

In their pre-review submission, the HSC Board provided material that indicated trusts had been directed to implement this recommendation. The HSC Board explained that a clear message had been communicated to all trusts, advising that there should be no allocation of short break support without the completion of a carer's assessment.

Carers' assessment data is being returned to the HSC Board on a monthly basis as part of the delegated statutory functions monitoring. The HSC Board has indicated that this information will be used to give a better understanding of the reasons for variations, with a longer term aim to ensure more consistent use of carers' assessments within trusts.

In discussion, the HSC Board advised that trusts are reporting the number of assessments they have completed and are able to give information about the services they provide in response to this. However, trusts are not reporting services they are unable to provide, so there is no analysis of this.

Findings in Adult Services

The link between the allocation of short break provision and a carer's assessment had already been in place as part of the DHSSPS 2009 trust self-audit. Recommendation 119 from the Self-Audit of Carers Support is that trusts should "ensure services are provided on the basis of assessed need and balanced risk analysis". Trusts scored strongly on this audit requirement and it was not listed in any of the recommendations as an area where evidence was insufficient. When the HSC Board was asked to conduct the 2012 update of that audit, Recommendation 119 was not identified as one of the priority areas for improvement.

However evidence from HSC Board monitoring and carer feedback indicates that there is no automatic link between assessment and short break provision; or between support plan and short breaks. Measures, other than short breaks, can support carers and form a support plan, including access to information, provision

of equipment or signposting to local support groups. The professional challenge is to be innovative and to find support through local solutions.

The recommendation in the 2010 report requires the HSC Board to have a central point that holds information on all carers assessments for both adults and children so that this information can be used for managerial purposes.

The HSC Board advised that the centralised collation of this information has not been undertaken and they felt it questionable that this would inform the process of increasing access and ensuring equity. The HSC Board considers that more productive measures will be those that improve on the quarterly reporting of delivery and the performance management thereafter.

Findings in Children's Services

All referrals for short breaks are assessed under the UNOCINI framework and children in need information is collated and provided to the DHSSPS via Delegated Statutory Functions and Corporate Parenting reports.

The HSC Board, via the Children's Services Improvement Board (CSIB), has issued guidance regarding the interface with UNOCINI.

Adult and Children's Services: Trust Comments

Trusts advised the review team that they were currently providing the HSC Board with monitoring returns in respect of carers' assessments undertaken. This provides information on the numbers of carers' assessments undertaken, the numbers declined and the reasons for declining the offer of assessment. This information is currently being considered by the Carers Strategy Implementation Group to establish the reasons assessments are declined with a view to improvement in future uptake.

Trusts advised how they are providing guidance and training in relation to the requirement to complete carers' assessments and to ensure that the reasons for declining an assessment are recorded.

Trusts described various methods to help determine future needs for the service. This helps to focus on transitional arrangements from children's to adults services and is beginning to help provide a clearer image of the changing needs of those in receipt of short break support, their individual profiles and the needs for any specialist short break services. This, in turn, can feed into areas such as training and development to ensure that staff are equipped to deal with the needs of services users in the future.

4.6 HSC Board's Commissioning Statement of Intent

HSC Board Report (December 2010) Recommendation 6

The Board should produce a commissioning statement of intent in order to set the future direction for the development of respite care. This statement should emphasise the need to promote more community based (as close to home as possible) and integrated (using a variety of approaches) respite support with a consequent reduction in the volume of residential and nursing home placement.

In their pre-review submission, the HSC Board provided material that indicated that this recommendation is reflected by the key themes within TYC. The HSC Board stated they would seek to ensure these principles are articulated and taken forward within local and regional commissioning plans under TYC.

The HSC Board Commissioning Plan 2013/14¹⁰ states that the recent review of the provision of health and social care within Northern Ireland, Transforming Your Care (published in December 2011) contained a total of 99 recommendations resulting from comprehensive engagement and consultation with a wide range of stakeholders and analysis of the current provision of care.

Some of the key recommendations from the TYC review focus on providing care as close to home as practical; providing greater personalisation of care and more direct control, including financial control, over care for patients and carers; greater choice of service provision, particularly non-institutional services, using the independent sector, with consequent major changes in the residential sector.

A key commissioning priority for 2013/14 and beyond, is the development of a range of innovative and accessible services in the community to support people to live as independently as possible. Individuals will be supported to maintain good health and wellbeing, preventing the onset of illness and avoiding deterioration with any existing conditions. Primary care and community-based services will be enhanced, avoiding the need for people to attend hospital and ensuring that, when hospital care is necessary, they are able to be discharged from hospital as soon as they are fit to do so.

In its pre-review submission, the HSC Board provided the review team with copies of commissioner specifications for Child Health Services and for Family and Child Care. The review team assessed these documents and agreed they do promote community based support with a subsequent reduction in residential care.

In addition to this, the HSC Board provided a copy of the commissioner specifications for Carer Support/Short Breaks. This focuses mainly on the needs of the carer but it does also indicate an intention to reduce the current reliance on institutional provision of short breaks. The review team noted that the commissioning statement is being supported by residual demand funding.

¹⁰<http://www.hscboard.hscni.net/publications/Commissioning%20Plans/Commissioning%20Plan%202013-2014/Commissioning%20Plan%202013-2014%20PDF%203MB.pdf>

It is further noted that the HSC Board has a number of statements of intent and commissioning objectives within the 2013/14 commissioning plan in the following areas:

- Community Care and Older Peoples Services
- Physical and Sensory Disability
- Children and Families
- Learning disability

In relation to short break provision, these support the need to promote more community based (as close to home as possible) and integrated (using a variety of approaches) support with a consequent reduction in the volume of residential and nursing home placement.

For adults, within the draft terms of reference (October 2013) for the recently established Regional Short Break Development Group, the review team noted the following objectives for the future:

- enable carers to sustain their caring relationship and other important family and/or social relationships
- ensure that carers are treated as partners in the care of the person who is older, disabled or mentally ill; and are directly supported to continue caring when they have assessed needs
- increase the range of services available to carers for short breaks, including greater use of existing community services
- increase the number of carers supported by HSC and partners within the resources available

This is supported by a three year action plan (2013/16) which identifies the need to improve short break provision. The action plan contains 3 core objectives:

- improve access to short break provision
- increase the range of services available to carers on both open access and assessment of needs basis
- increase the number of carers regionally who are supported by the HSC and its partners

The review team found that the HSC Board's Commissioning Plan (2013/14) gives a commitment to the promotion of community care. In respect of the language used within the document, they were disappointed to find that the terminology of respite is still widely used throughout.

The review team welcomes the statements of intent within the 2013/14 commissioning plan and recognises that the challenge for the HSC Board is to ensure that in the future short breaks are provided within the community, closer to home and delivered using a variety of integrated approaches. This should lead to a reduction in the care home placements, in line with the aspirations of TYC.

Adult and Children's Services: Trust Comments

Trusts confirmed that they have had sight of the commissioning specifications through the HSC Board Commissioning Plan for 2013/14. They further confirmed that this is reflective of the requirement to promote more community based and integrated short break support with a consequent reduction in the volume of residential placements. This reinforces the additional requirements of TYC that have come to the fore since the original HSC Board report Respite Support was published in December 2010.

The review team concluded that recommendation 6 has been enacted but the language contained in future statements of intent should refer to short breaks and not respite.

5. Views of Voluntary Agencies regarding Short Break Provision in Northern Ireland

Interviews with representatives from voluntary agencies and patient representative groups were held to seek views about the current short break provision. Opportunities to share and discuss their views with HSC Board and the five HSC trusts were also explored.

The views obtained have been categorised as follows:

- The value of short breaks
- Range and quantity of short breaks in Northern Ireland
- Quality of short breaks in Northern Ireland
- Barriers preventing uptake
- Carer Assessment
- Engagement with the health and social care sector.

5.1 The Value of Short Breaks

All of the voluntary agencies spoken with described short breaks as being essential for the person and for the carer in providing relief and rest from the routine of caring.

Short breaks were described as crucial to both the carer and the person being cared for. It was felt that short breaks also provide a break for the entire family. While those in receipt of care often have a single carer, the contribution of other family members cannot be underestimated, particularly the support provided by siblings.

Voluntary agencies described how short breaks can make an enormous difference to carers' lives. Often a short break was described as a lifeline, as it allowed carers time to focus on themselves and address their needs. Whether a short break was provided in the form of overnight stay or a few hours each week, it allowed them time to deal with routine issues. It was felt that short breaks contribute to overall health and mental well-being. However, to ensure that this benefits the carer on a routine basis, short break provision must be regular and routine.

Representatives commented on how important it is for both carers and those in receipt of care to have access to a service that best suits their individual needs at a point in time. While carers accessed different forms of short break provision, it was suggested that short breaks should, first and foremost, be designed around the needs of the person in receipt of care.

5.2 Range and Quantity of Short Breaks in Northern Ireland

Agencies consulted indicated that there was an overall sense amongst the voluntary sector that there appears to be a lack of provision of short breaks and that demand seems to be outstripping supply. In particular, clients with specialist conditions are not being fully provided for and often care is not tailored to the needs of those in receipt of care.

For those in receipt of care with multiple conditions, finding a suitable short break place can be more difficult. Carers' who care for more than one person, find it difficult to access short breaks for each person in their care at the same time.

In terms of provision of short break care throughout Northern Ireland, a geographical inequity was described. Those spoken to recognised that it can be difficult to provide the same level of services in remote areas, due to factors such as cost and economies of scale. This was described as unmet need within the health and social care sector. Voluntary agencies indicated a willingness to explore partnership working with other agencies to help to provide more services in remote areas. The agencies also referred to a lack of crisis care and emergency short break provision and suggested that this could be due to a lack of planning for emerging crises and planned support.

An emerging view that levels of unmet need are increasing was raised. This may be due to the fact that people are living longer, or the incidence of long term conditions is increasing and many more service users are dependent on technology for their survival. There is a need to ensure that services are responsive to the increasing needs of service users and that staff working within short break services are adequately skilled to deal with the complexity of specific needs.

Of particular concern to some agencies were the transitional arrangements in place for those children moving from children's to adult services. Short break care in the facilities they have previously used cannot continue as they are regarded as adults. This can lead to a reliance on nursing and adult care homes that are neither age or developmentally appropriate.

In relation to the range of services, the voluntary agencies identified a need for a variety of short break options, across the spectrum from day care to residential care, as all of the options may be required at different times in an individual's life.

5.3 Quality of Short Breaks in Northern Ireland

Voluntary agencies reported that carers regularly tell them that the standard of short breaks can be variable. They felt that sometimes, due to lack of options and choice, carers have to take whatever is offered.

They described the need for reliable, quality short breaks that enrich the quality of life for those in receipt of care. Short break care needs to be provided in environments, with age appropriate stimulus and activities.

Those spoken with felt that, in order to allow carers to build trust in services, it is vital that those in receipt of care are safe, happy and well looked after. It is essential that short break care is a positive experience and beneficial for both the carer and for the individual in receipt of care. Evaluating short break care experiences afterwards was seen as crucial to ensure a quality service was being provided.

When a short break involves an element of nursing care for those with specialist needs, a suitable environment, staffed by personnel who are appropriately trained, is essential.

Agencies reported small innovative examples of good practice but confirmed that these are difficult to maintain as they are often resource intensive. They pointed out that ongoing financial support for these should be provided to ensure innovative ideas/proposals continue.

It was felt that more recognition should be given to the value of support provided by voluntary agencies when families request access to particular support, external to the clinical environment. All agencies reported a need for those health and social care organisations involved in planning, commissioning and providing to explore new options in short break care.

5.4 Barriers Preventing Uptake

Those interviewed talked about the difficulty of carers recognising their carer responsibility as a role in its own right. Many see this as a sense of duty to their loved one and, as such, are not always willing to ask for support from the health and social care sector. They feel that asking for help may be seen as an indicator of not being able to cope.

Often the carer will initially approach the voluntary sector for advice and support and this provision of a listening ear is seen as vital.

Agencies reported that a lot of carers are uncertain of the types of support available to them. There can also be a lack of information about available short break options and the admission criteria for short break services. In addition, the provision and eligibility criteria appear to be variable across each of the trust areas.

It was felt that the health and social care sector needs to do more in relation to providing information about the types of short break care available and criteria for accessing this, at the initial stages and at regular periods throughout the care journey. This information should include details of support that can be provided by the voluntary sector. A number of the voluntary agencies spoken with suggested they could help by sharing carer booklets on their websites, at no cost.

Agencies reported a lack of signposting both within HSC services, as well as from the HSC to the voluntary sector. Links do exist between some voluntary agencies

and with the Carer Co-ordinators in each trust. However, these appear to operate differently in each trust area.

Agencies felt that where there are opportunities for partnership working, these should be embraced. However, they also felt there needs to be an effort on the part of the wider health and social care sector to see what assistance voluntary agencies can offer.

Voluntary agencies, focusing on the individual in receipt of care, described how it can be upsetting for a person to accept the need for a short break. Some agencies described how accepting short break services is often seen by both the carer and those in receipt of a care, as a step in conceding that a condition is deteriorating, and results in a fear that, once short break services are required, the next step may be more intensive care requirements such as full time residential care. Others described how some carers feel that if they break their caring routine, this may cause problems when the recipient returns from the short break. Therefore, it is important to recognise the right of the person in receipt of care and whether they want to use short break care.

There are many personal issues for carers and those needing care to deal with before accessing short breaks, including feelings of guilt and a lack of trust or confidence in the services they are offered. Separation can be difficult for both parties and often the value of the short break is not great enough to overcome this barrier.

Due to an inequity of provision previously described, it can be difficult to find an appropriate short break facility. Location and geographical issues around provision of the short break can be a physical barrier to uptake. In addition, the available timing of the short break may not always be of benefit to the carer.

Some agencies felt that those people who are not currently accessing short break services do not know what a short break is, or what it means.

Some examples outlined the difficulties individuals experience in trying to access short break care which lead to feelings of anger, as they feel their full-time caring responsibilities, and their contribution to keeping people out of institutional care, are not valued by the health and social care sector. This leads to the perception that there appears to be no value placed on them as a carer.

Carers have described a fear in respect of the quality of care provided, for example, ensuring that medication is being administered appropriately. If the care experience is not of an acceptable quality, this can lead to individuals not using this support again. It is vital that short breaks provide a positive experience for both the person in receipt of care and for the carer.

5.5 Carer Assessment

Throughout the engagement a number of issues around current carers' assessments were discussed.

Voluntary agencies reported that not everyone was aware of carer assessments and that access to them was variable. It was felt that assessment tools are not being used to full potential.

For those carers who had undergone assessments, some felt that the assessment can be a positive experience, while others described a reluctance to undertake an assessment as they feel the questions are quite intrusive. It is often felt that a carer's assessment can raise the carer's expectations, only to discover that nothing is available to address their specific needs.

It was felt that more could be done to raise awareness that carers' assessments consider all needs of the individual and are not specifically focused on the provision of short break care. For example, the carer's assessment includes a section about emergency planning and asks carers to think about who they could contact in an emergency. This allows debate in this area and helps to plan for emergencies which may arise. Raising awareness of the carer's assessment as a holistic tool could help counter-balance any negative perceptions.

5.6 Engagement with the Health and Social Care Sector

During the engagement, RQIA heard many good examples of localised working between voluntary agencies and specific trusts across NI.

Some of the larger voluntary organisations have representatives, or support service users, who are members of the Regional Short Break Development Group, the Children's and Young Peoples Strategic Partnership, the Children with Disability Sub Group and the Transitions Sub Group at the HSC Board. Those agencies felt that, while much of the work of the HSC Board groups has only recently been re-established, each of these groups has the potential to allow for the voice of the carer and those in receipt of care to be heard, in order to help shape future service delivery.

It is widely recognised that short breaks need to adapt to the individual, reflecting their changing needs. New options need to be explored and agencies described an anticipation that future engagement with the HSC Board will be positive and will bring about innovative thinking, thus improving how short breaks are delivered. There is a positive sense of commitment to participation on the various groups. However, it was noted that it is difficult at times to get information from the HSC Board about the work/progress of these groups. There were views that the work of the groups overlapped and that the same issues are often discussed at several of the groups.

Smaller voluntary agencies do not appear to have the same level of contact with the HSC sector and they feel they do not have opportunities to share the

experience of carers or to input into future planning with the HSC Board. Representatives told the review team that frontline staff can provide valuable insight into services and they felt that the HSC Board could benefit from enhancing relationships with the smaller voluntary agencies.

While most voluntary groups were aware of pockets of innovative work being taken forward, it was recognised that this is often driven by individual or small teams within trusts. There is a feeling that this is not led or directed in a strategic way by the HSC Board.

5.7 Vision for the Future

The interviews with those representatives from voluntary agencies and patient representative groups highlighted their passion about the value of short break provision and how beneficial this can be to both carers and those in receipt of care.

While agencies recognise that the health and social care sector has to work within existing parameters, they felt there is a need to become more innovative and flexible in meeting individual needs.

In summary, those spoken to felt that short break provision could be improved in the future by:

- proactive awareness raising/provision of information and signposting
- being more innovative
- providing choice/menu of options
- being planned in advance and provided on a regular basis
- being available at short notice in crisis situations
- examining ways to assess currently unknown need
- providing the right option at the right time in the most appropriate environment
- being suitable for all, including those with difficult/complex needs
- supporting people in their own homes
- moving forward with self-directed support
- reviewing the inequity in provision and cost of short breaks across NI
- provision of clearer information on funding allocations and assurances that this is shared appropriately between services
- recognising the value of low level interventions/shared experiences
- having access to reliable information to allow for future planning

6. Future Development of Short Break Provision in Northern Ireland

In June 2013 the Director of Social Care and Children at the HSC Board wrote to HSC trusts indicating that it was an appropriate time to begin to generate areas of reform and modernisation within short break care services.

As a consequence of TYC, the reform agenda has been further prioritised and the future challenge to the HSC Board will be to support more carers and to do so with a greater range of short breaks/short break opportunities.

At that time, the HSC Board recognised that the challenges were now more strategic than those originally set for the two Regional Respite Review Implementation Groups (RRIG) and, in response to this, the HSC Board established a new regional Short Break Development Group for adults. For children, it was agreed that work related to short breaks would be progressed by the Children with Disabilities Subgroup of the Children and Young People's Strategic Partnership (CYPSP).

Adult Services

The Short Break Development Group is now operational with a wider and more strategic membership and plans to embrace both the proposals contained in TYC and those that had begun to emerge from the original RRIG.

In the future there are plans to extend the membership to other agencies (e.g. local councils, the Department for Social Development and the Department for Regional Development) so that access to short break opportunities in the tourism, leisure, culture, and hospitality sectors can be explored.

The primary aim of this group is to develop, within existing resources, a regional model of carer support that is more equitable, improves efficiency, balances prevention and crisis response and achieves a positive experience for both carers and persons cared for.

The group has four key objectives which outline that modernised and reconfigured short break support services should:

- enable carers to sustain their caring relationship and other important family and/or social relationships
- ensure that carers are treated as partners in the care of the person who is older, disabled or mentally ill; and are directly supported to continue caring when they have assessed needs
- increase the range of services available to carers for short breaks, including greater use of existing community services
- increase the number of carers supported by HSC and partners within the resources available

The group will progress the following principles of modernisation:

- reform of statutory provision; review of domiciliary short break services and reduced use of statutory residential care settings
- shaping the market; using community development and procurement strategies to encourage a range of non-institutional services which will enhance choice and facilitate early intervention and greater flexibility
- incorporation of personalisation principles to the assessment of carers' needs, support planning and regular review
- maximise the use of forms of self-directed support (SDS), with greater access to information on short break choices and the explicit exercise of choice by carers

Local delivery of these strategic objectives will also be a matter for trusts and they must have arrangements in place to ensure local implementation and ensure local carer engagement.

In September 2013 at the first meeting of Short Break Development Group, the chair gave a summary of the background to the establishment of the group and detailed the previous work in relation to the HSC Board report Respite Support (December 2010). It was noted that work was retrospective by nature and that the priority now was to develop and improve short breaks within the vision contained in TYC. A three year action plan (2013/16) that identifies the need to improve short break provision was also presented.

Children's Services

Work related to short breaks for children is now being taken forward by the Children with Disabilities Subgroup of the Children and Young People's Strategic Partnership.

Future plans are outlined in a series of documents including:

- Children and Young People with Disabilities Action Plan (2011/14)¹¹
- Northern Ireland Children and Young People's Plan (2011/2014)¹²
- Transition to Adulthood for Young People with Disabilities Regional Sub-Group Action Plan (2011/14)¹³

As part of their objective to review short break provision, the Children with Disabilities Subgroup supported by the HSC Board and the DHSSPS coordinated a regional learning seminar on the area of short breaks. This seminar, held in 2011, looked at best practice across the UK.

In 2012 a national conference on short breaks was held in Scotland, supported by the Scottish Executive, and key staff from Northern Ireland were supported to attend. The regional learning and best practice endorses the development of the model of self-directed support (SDS) as a key foundation for the development of

¹¹ http://www.cypsp.org/publications/subgroups/cwd/cwd_action_plan_2011-214.pdf

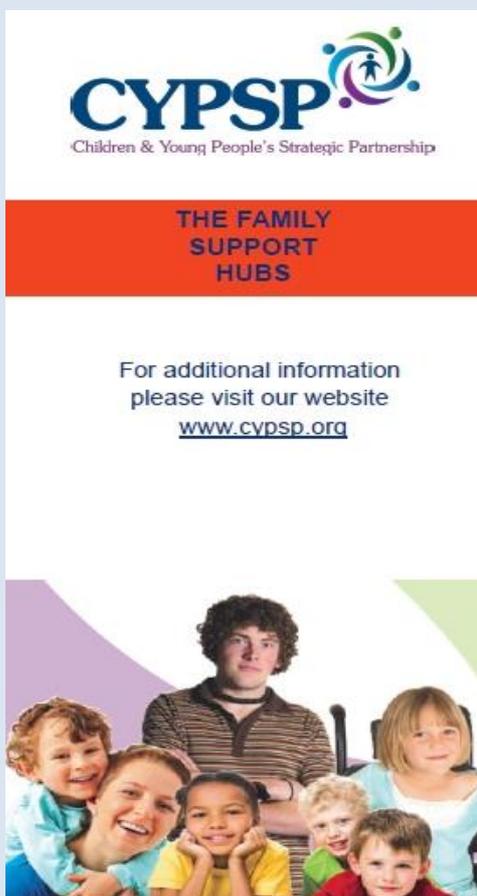
¹² http://www.cypsp.org/publications/cypsp/action-plan/cypsp_action_plan_2011-2014.pdf

¹³ http://www.cypsp.org/publications/subgroups/transition/cypsp_transition_draft_action_plan.pdf

services in the future. The HSC Board has since established, under direction of the DHSSPS, a SDS project structure designed to take forward the expansion of SDS in health and social care.

The NI Children and Young People's Plan 2011-2014 has identified the need for a network of Family Support Hubs in all the Outcomes Group areas. For the CYPSP this is an important part of delivering on the strategic theme of early intervention.

The primary objective of a family support hub is to provide the necessary co-ordination that ensures families, children and young people receive the right service at the right time. The aim is to avoid duplication and improve co-ordination of service delivery to individual families.



Family Support Hubs

Family support hubs provide early intervention family support services to vulnerable families and children/young persons aged up to 18 years.

A Family Support Hub is a multi-agency network of statutory, community and voluntary organisations who work directly with parents and children in a local area.

The hub can either provide early intervention services or work with families who need early intervention services but do not meet the threshold for statutory social work support.

The network accepts referrals of families who need early intervention family support and uses their knowledge of local service providers and the Family Support Database to signpost families with specific needs to appropriate services.

The specific purpose of the hub is as follows:

- To improve access to early intervention family support services by matching the needs of referred families to family support providers
- To improve co-ordination of early intervention family support services by creating a collaborative network of community, voluntary and statutory providers
- To improve awareness of early intervention family support services
- To assess the level of unmet need for early intervention family support services and inform the Trust Outcomes Group

The HSC Board has put a specific focus on young carers' issues and has established a Young Carers Sub Group to take forward work in this area. This was considered by the review team to be a good practice initiative.

The HSC Board commissions the young carers service currently provided by a consortium headed by Action for Children. A young carer's service is based in each trust area.

Young Carers Strategy

The Children and Young People's Strategic Partnership oversees a number of NI wide subgroups established to take forward integrated planning on a Northern Ireland wide basis, including a Sub Group on Young Carers.

Young Carers are defined as 'children and young persons aged up to 18 years who have a substantive caring role for a member for their family and children and young persons aged up to 18 years whose health or development is affected due to their caring responsibilities'.

Given the importance of their role within the family context and the effect that this level of responsibility may have on their development and emotional well-being, it is vital to ensure that Young Carers receive additional support they may require.

A Young Carers Action Plan (2011-2014)¹⁴ has been developed by the Regional Sub Group on Young Carers to draw together a plan for integrated commissioning of supports and services for young carers, which will improve their outcomes. Membership of the Group consists of representatives from the statutory, voluntary and community sectors and the participation of young carers and their families in all stages of this process is paramount.

The action plan sets out how the Young Carers Sub Group will contribute towards the implementation of the NI Children and Young People's Plan (2011/2014)¹⁵ and includes the priorities that need to be taken forward to improve the six high level outcomes for young carers, which are:

1. Healthy;
2. Enjoying, learning and achieving;
3. Living in safety with stability;
4. Experience economic and environmental wellbeing;
5. Contributing positively to community and society;
6. Living in a society that respects their rights.

¹⁴ http://www.cypsp.org/publications/subgroups/young-carers/young_carers_action_plan_2011-2014.pdf

¹⁵ http://www.cypsp.org/publications/cypsp/action-plan/cypsp_action_plan_2011-2014.pdf

This group has a long term view, through a focus on early intervention and integrated working, that young carers are, as far as possible, alleviated from their caring responsibilities to enable them to achieve the six high level outcomes.

Each of the five Young Carers Projects is required to put in place interventions relating to:

- Young carers themselves
- The families of young carers
- The wider systems within the young carer's life

These interventions are designed to achieve improvements in the following indicator clusters:

- Work to promote the identification of young carers
- Provision of information to young carers
- Assessing the needs of young carers
- Provision of services to young carers

A protocol for the assessment of young carers is being progressed through the Children's Services Improvement Board. This is designed to clarify the role of the young carers service and the role of the trust in assessing the needs of young carers. It is also designed to improve multi-agency response to the needs of young carers.

Young carers from the service have helped to develop a Think Family leaflet with the assistance of Participation Network.

There are two pieces of work currently being progressed under the heading of engaging with education to understand the needs of and help identify young carers.

1. A pilot training course for teachers to raise awareness of issues for young carers developed by the Young Carers Service. This is to be delivered in the Southern Education and Library Board area and is being developed by Action for Children. If successful, the intention is for a number of other workshops to take place. This is being developed through the young carers' subgroup of the CYPSP.
2. Carerstrust UK have developed a toolkit for use in schools to raise awareness on young carers' issues. The Young Carers subgroup of the CYPSP has agreed with Carerstrust UK that this can be adapted for NI. A multi-agency working group (including education) will undertake this work.

Both of these pieces of work are part of the Young Carers action plan developed by CYPSP.

7. Conclusions

Having assessed the pre-review submission and findings from interviews with key staff from the HSC Board and five HSC trusts, the review team concluded that there had been progress to varying degrees in taking forward the six recommendations from the HSC Board report *Respite Support* (December 2010). Developments had been taken forward by the two original Regional Respite Implementation Groups (RRIG) in adult and children's services.

While there had been an initial impetus in taking forward the six recommendations, this progress seemed to have fluctuated over time.

Progress made by the two regional groups was summarised, by the HSC Board, in a letter dated 21 May 2012 from the Director of Social Care and Children, HSC Board, to the Permanent Secretary at the DHSSPS. The review team considered that since this update, provided to the DHSSPS in May 2012, there seemed to have been a loss of momentum in addressing the outstanding requirements.

Following an internal review of existing groups within children's services in September 2012, an overlap and duplication had been identified, thus resulting in the children's Regional Respite Implementation Group being stood down. It was agreed that the outstanding recommendations of the report should be taken forward by the Children with Disabilities Subgroup of the CYPSP.

In June 2013 the Director of Social Care and Children, HSC Board wrote to HSC trusts advising that, as a consequence of TYC, the reform agenda had been prioritised and the strategic challenge for HSC Board would be to support more carers, and to do so with a greater range of short break opportunities. It was further stated that the challenges were now more strategic and innovative than those originally set for the current adult Regional Respite Implementation Group (RRIG). In response to this, the HSC Board established a new regional Short Break Development Group.

While the review team recognises the importance of the reform and modernisation agenda, they feel that this cannot be fully pursued until the original six recommendations from the HSC Board report *Respite Support* are fully implemented.

The review team considers that the current working group structure is appropriate to progress future innovation and reform in the areas of short breaks, however, the HSC Board should not lose sight of the original six recommendations and the work required to ensure these are implemented.

The review team recommend that senior officers within the HSC Board should set up a short life working group to consider the full implementation of the original six recommendations.

The remit of this group should include:

- defining and agreeing a menu of short break services with agreed associated coding structures so trusts can ensure information on short breaks can be compiled in terms of activity, cost and quality
- development of a regional reporting template, to include expenditure information associated to short break activity
- review by both the HSC Board and the HSC trusts of the new community information systems to ensure they take cognisance of regional reporting requirements
- agreement of a way forward in relation to a carer's assessment tool to support the current NISAT tool in adults services

RQIA Recommendation 7:

Senior officers within the HSC Board should set up a short life working group to reconsider the completion of the original six recommendations from the 2010 HSC Board report Respite Support. A report outlining final consideration should be produced for the DHSSPS by the end of March 2015.

8. Summary of RQIA Recommendations

RQIA Recommendation 1:

The HSC Board should issue a clear directive to HSC trusts, confirming the requirement to use the terminology of short break, for both adult and children's services, with immediate effect.

RQIA Recommendation 2:

The HSC Board should continue to review the definitions and guidance for monitoring data, for both adult and children's short break provision, in order to ensure that these reflect the modernisation of services provided across the HSC.

RQIA Recommendation 3:

The HSC Board should work with the trusts to ensure that robust systems are put in place to monitor expenditure, funded by allocations from the DHSSPS and the HSC Board, in relation to all short break provision across both adult and children's services by the end of March 2015.

RQIA Recommendation 4:

In relation to community information systems at trust level; the HSC Board should provide specific direction, to trusts, in respect of the management reporting requirements for activity and expenditure data for both adult and children's short break services which are funded by allocations directly from the DHSSPS and the HSC Board.

RQIA Recommendation 5:

The HSC Board must ensure that monitoring is developed further in the future, and designed to evaluate the quality of the services being provided across both adult and children's services.

RQIA Recommendation 6:

The HSC Board must ensure that the original Recommendation 3 is enacted in full as a priority; and a process developed to monitor and address the inequities in provision of short break support.

RQIA Recommendation 7:

Senior officers within the HSC Board should set up a short life working group to reconsider the completion of the original six recommendations from the 2010 HSC Board report Respite Support. A report outlining final consideration should be produced for the DHSSPS by the end of March 2015.



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