What Good Integrated Care Looks Like in Transition

NNPCF Steering Group
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# 1 Document

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2 Purpose

The NNPCF have been asked by the Children and Young People Health Outcomes Forum (CYPHOF) if we could produce a short paper which considers:

“What good integrated care should look like in transition, and how that can be measured from the perspective of parent carers of disabled children across a broad range of disability / impairment.”

There is specific interest in the NNPCF’s view related to Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs).

Whilst putting this paper together and considering the Health outcomes, the authors were mindful of work being undertaken nationally in other areas with regards to transition especially work in respect of the Children and Families Bill. The authors were mindful that although this response is primarily about integration of care within health there is a larger landscape to consider, involving education, social care, independent living, leisure and so on.

3 The National Network of Parent Carer Forums

NNPCF was launched in 2011, and is funded by central government. The NNPCF membership is made up of parent carer forums of which there is one in almost every local authority area in England. Each parent carer forum in receipt of the Department of Education participation grant is a member of the NNPCF.

The function of the NNPCF is to develop cohesive good practice and effective participation and a solution focussed approach at all levels, locally, regionally and nationally. Annex D demonstrates our structure and sphere of influence.

The NNPCF is a network of local forums meeting in regional settings, working together to effect local and national service improvement. The steering group of the NNPCF is made up of representatives of the nine regions. The aims of the NNPCF are:

- to ensure that good practice, knowledge and shared expertise about parent participation continues to grow and strengthen,
- to develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer forums across England and
- to strengthen pan disability, parent lead model of local forums and boost our collective voice.
4 Context

1 In October 2004 the Department of Health published National Service Framework for Children, Young People and Maternity Services (the National Framework). Under the heading ‘Standard 4’ the National Framework says:

‘All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood’.

‘Transition to adult services for young people is planned and co-ordinated around the needs of each young person to maximize health outcomes, their life chance opportunities and their ability to live independently – this is particularly important for disabled young people or those with long-term or complex conditions.’

Under the heading ‘Standard 8’ the National Framework says:

‘Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives.’

It also says: ‘Multi-agency transition planning takes place to improve support for disabled young people entering adulthood’.

2 Following the “Aiming High for Disabled Children – Better Outcomes for Families” programme in May 2007, all local authorities should have produced and published a “Transitions Protocol” by March 2011. This protocol should have established a route for disabled children and young people through from Education to Employment. Some protocols covered transition into adult social care and very few, if any, addressed health.

3 The NNPCF is also aware of the NHS Mandate to the Commissioning Board identifies the need for improvement in this area:

“…there is a particular need for improvement, working in partnership across different services... in supporting children and young people with special educational needs or disabilities. The Board’s objective is to ensure that they have access to the services identified in their agreed care plan, and that parents of children who could benefit have the option of a personal budget based on a single assessment across health, social care and education.”


This also links to the Health Outcomes Forum recommendation to develop inter alia a new outcome measure on integrated care for inclusion within the NHS Outcomes Framework.
4 Other examples of related work include Allan Colver from Newcastle University who is leading a research project on transition. More details can be found at: http://research.ncl.ac.uk/sparcle/index.htm

Early Support have also written widely about the importance of key working through the lives of children and young people with disabilities. Finally Together for Short Lives have recently been commissioned by the Department for Health to undertake a three year project to support the work of the Together for Short Lives Transition Taskforce.

5 What is integrated care?

5 NNPCF are aware of work undertaken by National Voices on defining integrated and co-ordinated care. They include a series of statements that seek to address some of the fears raised by children, young people, parents, carers and their advocates, including:

- When I use a new service, my care plan is known in advance and respected.
- When I move between services or settings, there is a plan in place for what happens next.
- I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.
- I am given information about any medicines I take with me – their purpose, how to take them, potential side effects.
- If I still need contact with previous services/professionals, this is made possible.

Details can be found at: http://www.nationalvoices.org.uk/defining-integrated-care

6 For integrated care, it is worth pointing out that there is already a validated parent completed questionnaire-based measure of the extent to which services are family centred and integrated (Measure of Processes of Care – MPOC) see http://www.canchild.ca/en/measures/mpoc56_mpoc20.asp. This has been tested in the UK and evidenced accordingly: http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2214.2003.00314.x/abstract;jsessionid=34A325E1E4303E0ACB79C6986A18A098.d01t03

We are very aware that outcome measures have to be properly considered and go through proper processes - MPOC obviously ticks those boxes. At the same time, there is too much information in it for parent carers and we are not sure it measures the right things. It is also wholly unclear who would coordinate these questionnaires.

The MPOC questionnaire also just asks a series of questions. There is no "SO WHAT" about it and there does not appear to be any feedback, recourse or plan for forward action. We feel there should be more “yeses” and “nos” since integrated care including transition should be clear cut.
6 A broad range of disabilities/impairments

7 The young people going through transition will have a range of diagnoses, comorbidities and health needs. These will include children and young people with:

- Sensory and physical conditions
- Cognitive and learning disabilities
- Acute and long term medical and life limiting conditions.
- Emotional, social and behavioural disorders

8 Young people with these diagnoses will access an array of health services from a range of different places depending on the diagnoses and comorbidities. This will include:

a. Primary
b. Community
c. Acute Hospitals
d. Specialist Centres and hospitals.

9 Children and young people with more complex disabilities and comorbidities will have to access multiple specialists in different settings. They will be taking multiple prescribed and other medicines. They may not see their GPs in Primary Care very often. The complexity of health needs and numbers of health and other professionals that can be involved for individual young people across these settings can be numerous and interconnected as demonstrated in the diagrams below.
7 Transition pathway

10 There is already established a generic transition pathway (Annex B) at least for children and young people with more complex needs and disabilities. The aim is always to start early from Year 9 or possibly year 8 in some cases although experience demonstrates that this tends not to be the practice. Additionally the process currently tends to be more education driven with little or no involvement from health or even possibly social care. Often assessments from social care about their level of involvement based on the young person’s potential eligibility for adult social care can be perfunctory and limited. It is hoped and expected that this will change when the new SEN changes become law from 2014. In terms of what parent carers would see as good integrated care in transition, we would expect:

- Starting early as the process is supposed to.
- Understanding our children and their needs totally (so no outstanding or incomplete diagnoses)
- Information, training and support for parents and their role in the process.
- Health, education and social care all involved as well as individual elements.
• Comprehensive multi agency transition process available for all children with health needs and disabilities (not just those with more complex needs).
• Health elements clearly coordinated across all areas and with a lead professional;
• Clear processes for Continuing Care.
• Planning for a real meaningful life in adulthood, not sitting at home- interaction with peers and participation in local community.
• Choices that reflect high expectations by and for the young people and access to training or support to be able to make choices and have their voice heard.
• Person centred transition pathways with solutions that are unique, appropriate and relevant.
• Access to personal budgets with clarity and choice about how they will be managed.

This transition pathway process enables all stakeholders to have an understanding of the issues involved for the young people, it opens up appropriate lines of communication and establishes a transition plan to which everyone is signed up to.

11 There needs to be integration within health as well as across all the areas of education, health and social care. Integration with and within health should introduce the role of a cross-agency lead professional who has the responsibility and authority to make sure that there are:

• clear efforts to involve young people and their parent carers in decisions
• recommendations for all health needs for adult services/primary care on what health services and are needed after 18/19
• clear pathways to those
• referrals made (rather than parents doing it or assuming parents/young people understand what they have to do).

The lead professional should have the responsibility and relevant authority to ensure this occurs and the plan is delivered.

12 In terms of the process, parents also consistently remark that:

• Parent carers and their children should be involved at all stages of the process
• There should be better information about services and support
• Early indication of the need to refer to the Mental Capacity Act 2005 should be considered.
• There needs to be a clear understanding as to the support needs and aspirations of the young person and this can be determined using the knowledge and experience of the parent.
• There must be consistent and clear levels of communication at all times.
8 The Family

There needs to be more understanding of the personal challenges, societal barriers and discrimination families with children with impairments and disabilities face more broadly.

From the point of diagnosis children and their families are presented with a series of challenges which are addressed with the support of a vast array of services in Health, Education and Social Care.

The challenges faced are alleviated by the services they are introduced to depending upon the nature of their child’s condition.

Parents refer to support in areas of:

- The provision of impartial information, advice and support
- Specific skills training to use medical equipment, manage sleep
- Support with developing positive behaviour, healthy eating
- Looking after themselves including safe lifting and handling techniques
- Developing opportunities for peer support and management of stress

However these positive interventions can often be clouded by the many difficulties faced by families caring for a disabled child, which can include:

- **Families with disabled children face challenges on different levels**
  - Negative perceptions of disability.
  - (Sometimes) family rejection.
  - Families deal with disability in different ways and may need appropriate support to manage their situation.
  - Wider communities (including faiths) not always supportive or inclusive.
  - Societal discrimination
  - Physical barriers to places, goods and services
  - Bullying and harassment
  - Poor or inappropriate housing
  - Poverty and financial hardship

- **Health**
  - Often pathways to diagnosis are not developed, not clear and too slow
  - Lack of understanding of and investment in early intervention in health
  - No prevention e.g. sleep, behaviour, eating
  - Limited support – e.g. around and post diagnosis, psychological conditions
  - Passed to education, who may not understand needs
  - No integration of health needs
• **Health, education and social care systems can add to burdens on families**
  o Families reaching or engaging with services themselves
  o Unable to get help from right services at right time
  o Silo mentality
  o Passing the buck
  o Lack of joined up outcomes
  o Family break down
  o Effects on children and young people in terms of less long term stability, happiness and poorer management of long term conditions

• **Choice and Control**
  o Genuine choice and understanding of service availability (e.g. many families want services from social care)
  o Access to Universal Services and “ordinary” leisure facilities
  o Confusion
  o Families want “ordinary” lives; whatever ordinary is.
Despite the need for a common process and a common set of success measures, there needs to be recognition that children with different severities of learning, physical and other disabilities will commence the process with different objectives and come out of the process with equally different outcomes.

Services must be mindful of the need to be flexible, mobile and responsive to the variety of needs. Parents will need support in relinquishing responsibility for their children (and where necessary be given support and assurances when this happens).

All the children and young people have to be able to achieve their own goals in a safe environment that is established to suit them. However during and after the process services must recognise the value of their parent’s knowledge and contribution and the essential role they play in the lives of their children.

These underlying issues translate into the following PREMS and PROMS

9.1 PREMS

- We understand the process, we know who is involved and we know what is expected of all professionals and within what timescales
- We are supported by a key worker / lead professional or case manager and have clear understanding of eligibility for services, and redress opportunities where we do not believe these are fairly applied or acceptable thus reducing the need to “fight” for any service.
- A lead health professional clinician is coordinating and integrating all the care and the work of other health professionals across different settings
- We are confident about the future for ourselves and our Young Person
- We are confident that all adult service professionals understand our Young Person’s needs and will meet them
- The right professionals are involved at the right time during the process

9.2 PROMS

- Family and Young People feel involved and have had their future aspirations and what is important to me and for me list identified and met (from Year 8)
- Young People transition smoothly into adulthood with no gaps in service provision
- Young People will lead fully fulfilled lives
- Plans are in place for current and ongoing health needs including a written agreed history that includes past medicines, surgery, other interventions etc
- A communication passport is in place if needed
There are named and identified consultant(s) or lead health professional identified who will be responsible for the health care of the young person before they are discharged from children’s health services.

Plans are in place for education, independent living and leisure, including for modifications if needed.

Our Young People fully understand the services available to them and can exercise genuine choice.

Our Young Person has appropriate access to advocacy if needed.

All relevant professionals are trained to support our Young Person.

Everything is reviewed regularly.
10 Conclusion

In addressing the question posed by the Children and Young People Health Outcomes Forum:

“What does good integrated care look like in transition, and how can that be measured from the perspective of parent carers of disabled children across a broad range of disability / impairment.”

We have concluded that this can be summed up in one phrase:

“The key factors for success seem to be agreement about the key outcomes, united efforts to achieve them and clarity about who is doing what.”

The NNPCF believe that the “PREMS” and “PROMS” identified in section 8 above go a long way to supporting measurement of the successful delivery of transition for each child or young person and their families who have to go through the process.

Above we have been able to define the context of the issues that are faced and clarified the current landscape in which we are all working. It is evident that transition is not a clear cut prescriptive process and each case is likely to have its own uniqueness. The measures suggested should be used to ensure that the process for each child has been achieved.

Using the similar principles of the “Measure of Processes of Care” MPOC (See Annex C) it should be possible to discover both during and after the process from parents, carers, young people and service providers how well the process is going or has gone. NNPCF suggest however that this should go further than the MPOC approach in three ways:

1. After review and feedback an action plan should be established for the individual to ensure that any issues are addressed and resolved.
2. All feedback from all transitions processes should be collated locally to evidence good and poor practice; thus enabling local services to improve their approach where common themes become evident.
3. A national picture can be drawn up of effective transition from local authority evidence which can be used to drive national policy or support commissioning as necessary.

NNPCF would be keen to continue to work with CYPHOF more closely to support the delivery of these suggested measures. With special emphasis on this report NNPCF believe that we can continue to contribute to any further discussions that might arise.

NNPCF would also welcome the opportunity for further opportunities to work with the CYPHOF.
10.1 Authors

This report has been produced by the National Network of Parent Carer Forums, based on our understanding and knowledge of our members, parent carers of disabled children who are linked to parent carer forums across England. The document has been contributed to by Members of the NNPCF Steering Group particularly, and written by:

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### 11 Annex A: New Commissioning Arrangements

<table>
<thead>
<tr>
<th>Clinical Commissioning Groups</th>
<th>Local Authorities</th>
<th>NHS Commissioning Board</th>
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| • Community health services (inc rehabilitation, speech and language, continence, wheelchair services) | • Healthy Child Programme (School Age)  
• School Nursing  
• National Child Measurement Programme | • Healthy Child Programme 0-5  
• Health Visitors  
• Family Nursing  
• Antenatal/newborn screening  
• Immunisation  
• Promoting early diagnosis as part of primary care |
| • Promoting early diagnosis as part of community health services and outpatient services | | |
| • Acute Care | • Specialised services  
• GPs | |
| • NHS data collection and information reporting systems | • NHS data collection and information reporting systems | |
| • Mental Health Services | | • Some specialised mental health |
| • NHS Continuing Healthcare  
• Services for people with LD | | |
12 Annex B: Generic Transition Pathway

This generic pathway provides an expected route for Children, Young People and their families through the transition process:

**Transition Pathway**

**Year 8 (age 12-13)**
- **TRANSITIONS WORK BEGINS**
  - Statutory SEN statement review.
  - Person-centred approach introduced.
  - Help given to set up a circle of support.

**Year 9 (age 13-14)**
- **TRANSITIONS REVIEWS FOR ALL YOUNG PEOPLE WITH ADDITIONAL NEEDS**
  - Consider:
    - Access to work experience.
    - Eligibility for Fair Access to Care.
    - Existing service provision and cost.
    - Appropriate post-16 provision.
    - Future provision as an adult.
    - Referral to appropriate adult services.

**Year 10 (age 14-15)**
- **TRANSITIONS REVIEWS**
  - to be attended by childcare worker, adult worker, post-16 providers and other appropriate support services. Ensure that:
    - Transition plan agreed.
    - Actions for individual workers/services.
    - Timescales documented.
    - Carers’ assessment offered.

**Year 11 (age 15-16)**
- **TRANSITIONS REVIEWS**
  - To continue especially if the young person is still in school. Ensure that:
    - Community Care assessments and care planning to be arranged as appropriate.
    - Personal budgets are discussed.
    - Gaps are identified and appropriate actions are planned.

**Year 12 (age 16-17)**
- **TRANSFER TO ADULT SERVICES**
  - If the person meets the eligibility criteria for the local authority. Transitions reviews to continue especially if the young person is still in school.
    - Community Care assessments and care planning to be arranged as appropriate.

**Ages 19-25**
- **PREPARATION FOR TRANSITIONS**
  - Young people with additional needs identified.
  - Parents and young people informed of processes.
  - Child and adult services informed.
  - Person-centred approach introduced.

**Year 13 (age 17-18)**
- **PLANNED CONTINUATION OF ADULT SERVICES**
  - By all services already involved.
  - Any additional services alerted.
13 Annex C – MPOC – Measure of Process of Care

The purpose of the MPOC is to assess parents' perceptions of the care they and their children receive from children's rehabilitation treatment centres. It is a means to assess family-centred behaviours of health care providers.

Validated on samples of parents whose children range in age from 0 to 17+ years and who had a variety of neurodevelopmental disabilities or maxillofacial disorders.

MPOC contains 56 items which have five factor analytically determined scales:

- Enabling and Partnership
- Providing General Information
- Providing Specific Information about the Child
- Coordinated and Comprehensive Care for the Child and Family
- Respectful and Supportive Care

Various studies of MPOC-56’s reliability and validity have been conducted. These demonstrated good internal consistency (Cronbach's alpha ranging from .63 to .96) and test-retest reliability (intraclass correlation coefficients ranging from .78 to .88). Validity has been shown with: (a) positive correlations between MPOC scale scores and a measure of satisfaction, and (b) negative correlations between MPOC scale scores and a measure of the stress experienced by parents when dealing with their child's treatment centre. Also, responses to MPOC indicate that various components of service provision are experienced differently by parents, with data showing variations across scale scores by both individuals and groups of parent respondents. The MPOC process was recently used to great effect in the Together for short lives “Big Study for Life-Limited Children and their Families”.

http://www.togetherforshortlives.org.uk/professionals/projects/project_one

For each item parents respond to a common question: "To what extent do the people who work with your child...". A 7-point response scale is used, with the following response options available: 7 indicated that the service provider engaged in this behaviour "to a very great extent", 6 = "to a great extent", 5 = "to a fairly great extent", 4 = "to a moderate extent", 3 = "to a small extent", 2 = "to a very small extent", and 1 = "not at all". A score of 0 indicated that the item was "not applicable".

A respondent's data yield five scores, one for each of the factors or scales. There is no total score. A scale score is obtained by computing the average of the items' ratings. Instructions for scoring are included in the manual.

Further details are available at: www.canchild.ca/en/measures/mpoc.asp
Each forum includes parent carers with a full range of experiences in Health, Education and Social Care as their children have a wide range of conditions.

Parents in the network total over 52,000; they contribute to Local, Regional and National consultations.

The NNPCF are involved in a wide range of national groups. These are more fully described in our own progress report which was published in March 2013.

It can be downloaded on-line from the resources page on our web site: http://www.nnpcf.org.uk/resources

We continue to develop closer working relationships with health at all levels, including local working with CCGs.

Further details about the NNPCF can be found on our web site www.nnpcf.org.uk.

(Please note that at the time of writing we are currently updating our site and it may change without prior notice.)