

Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011–2015

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Executive Summary

December 2016

This executive summary gives an overview of the findings from an analysis of child- and parent-reported outcomes and experience from child and young people's mental health services in the UK. The full report is available at www.corc.uk.net.

Context

- **Some areas of physical health care have been able to use data to drive service improvement.** Historically there has been a lack of data in child mental health.
- **Measuring outcomes and experience in child mental health from the perspective of child and parent is challenging** due to the diversity of population, perspectives, measures, metrics and a lack of counterfactuals, comparisons and quality data.
- **Data are from cases seen in services which were part of a service transformation initiative.** Child and young people's mental health services sought to embed evidence-based treatments, user participation and use of routine child- and parent-reported outcomes and feedback systems.
- **There were challenges to implementation and data collection.** Historically underfunded services and lack of developed infrastructure combined with increased demand of around 11% per annum, alongside service cuts of up to 75% and major IT difficulties, as well as practitioner concerns about use of measures, resulted in significant challenges for services and for data collection.

Data quality

- **Limitations of data quality and quantity mean all findings have to be treated with caution.** In particular, given the unknown (unmeasured) bias due to missing values and the unknown selection mechanisms into different outcome measures, these data are not necessarily applicable to the wider child mental health service population.
- **This dataset is made up of data that are flawed, uncertain, proximate and sparse (FUPS).** Many might argue that, in the light of this, such data are not safe to use. CORC argues that whilst recognising the limitations and cautions, FUPS data are likely to be all we have for some time and, with care, can be used to support dialogue about how to set realistic

targets for child mental health outcomes in the future, which can inform service improvement and development.

Measures

- **21 children and 15 parent-reported scales were used in this report (19 child and 13 parent scales included thresholds).**
- **Different scales use different approaches to calculate thresholds.** This presents challenges for comparing across scales and populations.

Data completion

- **Target for data completion in relation to key outcome metrics was not met.** A target of 90% of all closed treatment cases (at least one paired child- or parent-reported scale with thresholds, and a measure of attainment and attendance in relation to employment education or training) was set.
- By June 2015, 4,850 (21% of closed treatment cases) had a paired scale with thresholds, as well as information on attainment and attendance.

Demographics

- **96,325 cases seen:** age range 0–25, mean age 12 years, 82% white, 52% female.
- Of the 96,325 cases seen, 42,798 (44%) had practitioner ratings of at least some case characteristics. Of these, approximately:
 - **1 in 2 had family relationships difficulties**
 - **1 in 3 had self-harmed**
 - **1 in 5 reported parental health issues**
 - **1 in 8 had experience of abuse.**

Completed cases

- **23,373 closed treatment cases** (seen for more than just assessment). Of these, 17,056 (73%) had completed a child- or parent-reported scale with thresholds.
- Of the 17,056 closed treatment cases with child- or parent-reported scale with thresholds, 15,537 had scores on one or more scales at outset. Of these, approximately:
 - **9 in 10 of those with completed scales with threshold at outset were above threshold on one or more child- or parent-reported scales at the start of treatment.**
- Of 31,037 cases where a case-mix algorithm based on practitioner ratings was applied, approximately:
 - **1 in 2 had problems not readily assignable to a NICE-recommended treatment.**

Outcome and experience

Child-reported outcomes were more likely to be from older and female respondents than being representative of the full sample. Parent-reported outcomes were more likely to relate to younger and male children than being representative of the full sample.

A range of approaches was used to consider outcomes and experience for the 23,373 closed treatment cases.

Experience of service

- Of the 3,196 cases (14% of all closed treatment cases) where children reported on their experience of the service, approximately:
 - **4 in 5 endorsed receiving good help**
 - **3 in 5 endorsed convenient appointments.**
- Of the 2,698 cases who had completed a course of treatment and where parents reported on their experience of the service (12% of all closed treatment cases), approximately:
 - **9 in 10 endorsed receiving good help**
 - **7 in 10 endorsed convenient appointments.**

Movement towards achieving goals

- Of the 2,784 cases (12% of all closed treatment cases) who had paired data on child goals, approximately:

- **9 in 10 reported movement towards the agreed goals.**
- Of the 686 cases (3% of all closed treatment cases) who had paired data on parent goals, approximately:
 - **9 in 10 reported movement towards the agreed goals.**

Considering outcomes for closed treatment cases with at least one child or parent report scale above threshold at outset:

“Recovery” rates were calculated using an adaptation of the Adult IAPT approach.

- Of the 5,896 cases (25% of all closed treatment cases) with paired child report data where one or more scales were above threshold at outset (on average four scales completed per child), approximately:
 - **1 in 3 children “recovered”** (no scale above threshold at end of treatment).
- Of the 3,707 cases (16% of all closed treatment cases) with paired parent report data where one or more scales were above threshold at outset (on average four scales completed per child), approximately:
 - **3 in 10 parents indicated child problems “recovered”** (no scale above threshold at end of treatment).

Reliable improvement rates were calculated using an adaptation of the Adult IAPT approach.

- Of the 5,896 cases (25% of all closed treatment cases) with paired child report data where one or more scales were above threshold at outset (on average four scales completed per child), approximately:
 - **1 in 2 children reliably improved** (amount of change in score more than likely due to measurement error and no reliable change in the opposite direction on any scale)
 - **1 in 10 children reliably deteriorated** (counted as deteriorated if happened on any scale).
- Of the 3,707 cases (16% of all closed treatment cases) with paired parent report data where one or more scales were above threshold at outset (on average four scales completed per child), approximately:

- **2 in 5 indicated child problems reliably improved** (amount of change more than likely due to measurement error and no reliable change in the opposite direction on any scale)
- **1 in 10 indicated child problems reliably deteriorated** (counted as deteriorated if happened on any scale).

Reliable “recovery” rates were calculated using an adaptation of the Adult IAPT approach too.

- Of the 5,896 cases (25% of all closed treatment cases) with paired child report data where one or more scales were above threshold at outset (on average four scales completed per child), approximately:
 - **1 in 4 reliably “recovered”** (all scales below threshold at the end of treatment with reliable improvement in scores on at least one

measure which also shows “recovery” and no measure showing reliable deterioration).

- Of the 3,707 cases (16% of all closed treatment cases) with paired parent report data where one or more scales were above threshold at outset (on average four scales completed per child), approximately:
 - **1 in 6 indicated child problems reliably “recovered”** (all scales below threshold at the end of treatment with reliable improvement in scores on at least one measure which also shows “recovery” and no measure showing reliable deterioration).

Other analyses were also undertaken, including pre-post effect sizes for each measure with paired data available, and the added value score metric for paired data from the parent-reported Strengths and Difficulties Questionnaire. These can be found in the full report.

Concluding remarks

- This report is the first analysis of routinely collected child- and parent-reported outcomes and experience data collated from 75 mental health services in England.
- A range of outcome measures was used for the primary purpose of informing clinical decision-making with individual children and parents.
- In the absence of a commonly agreed method for analysing the data at a national level, several approaches to estimating outcomes were applied. Each method indicated different levels of change in the mental health, wellbeing or personal goals of a selected sample of children and young people using services.
- The findings are hindered by poor data completeness and the lack of a comparator group and should therefore be interpreted with caution.
- Although the findings are based on data that are flawed in a range of ways, and with a high degree of missing data (which we

have termed FUPS), they are the best currently available and should be used carefully to support dialogue about outcomes.

- CORC recommends this report is used to inform facilitated stakeholder discussions involving practitioners, funders, service users, policy makers and others. Key topics for consideration in such facilitated discussions might include the appropriate metrics for considering outcomes and appropriate targets for the given metrics.
- Better quality data on outcomes and experience must be facilitated and incentivised to aid review and development of services. To achieve this, leadership focus, improved IT systems, better staff training and stronger incentives may need to be in place.

This report and executive summary should be referenced: Wolpert, M., Jacob, J., Napoleone, E., Whale, A., Calderon, A. & Edbrooke-Childs, J. (2016). *Child- and Parent-reported Outcomes and Experience from Child and Young People’s Mental Health Services 2011–2015*. London: CAMHS Press.