

# The effectiveness of a parent-held record for disabled children

**Submission date**

23/01/2004

**Recruitment status**

No longer recruiting

☐ Prospectively registered

☐ Protocol

**Registration date**

23/01/2004

**Overall study status**

Completed

☐ Statistical analysis plan

☒ Results

**Last Edited**

22/02/2008

**Condition category**

Mental and Behavioural Disorders

☐ Individual participant data

**Plain English summary of protocol**

Not provided at time of registration

## Contact information

**Type(s)**

Scientific

**Contact name**

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## Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers

MCH 14-11

# Study information

## Scientific Title

### Study objectives

To test whether a child health record designed for pre-school children with a disability would:

1. Be used
2. Be valued by carers
3. Change the perception of the health care received by the child
4. Influence the amount of communication between the family and a professional who is seeing their child

### Ethics approval required

Old ethics approval format

### Ethics approval(s)

Not provided at time of registration

### Study design

Randomised controlled trial

### Primary study design

Interventional

### Secondary study design

Randomised controlled trial

### Study setting(s)

Not specified

### Study type(s)

Quality of life

## Participant information sheet

### Health condition(s) or problem(s) studied

Mental and behavioural disorders: Behavioural disorders

### Interventions

The intervention was a parent-held record for the parents of disabled children in which they could record contact details of the professionals seeing the child, the child's medical conditions and any medication and equipment used. A diary section allowed parents and professionals to record the child's progress and programme. There was also information about organisations relevant to children with disability. This was a quantitative individual controlled trial of AB design in which outcomes after six months without the intervention were compared those after a six-month intervention period. The participants were randomly allocated to three groups as follows:

Group 1: compared periods without and with the intervention

Group 2: measured any change without the intervention due to the passage of time

Group 3: estimated any effect due to the assessment after the first period without the intervention in Groups 1

**Intervention Type**

Other

**Phase**

Not Specified

**Primary outcome measure**

At the end of the study, copies of the records were examined and the number of entries was taken as a measure of their value to the users. The parents also completed a questionnaire about the value of the record. The way families viewed their child's health care was tested by experimental control using a questionnaire before and after the intervention. At the same times, the amount of communication between the parents and professionals was assessed by both parties completing an identical questionnaire about the child; the similarity between their replies was taken to be a measure of communication.

**Secondary outcome measures**

Not provided at time of registration

**Overall study start date**

01/01/1996

**Completion date**

31/12/1999

**Eligibility****Key inclusion criteria**

The participants were randomly selected pre-school children in the community who had been notified to the Education Department as likely to have special educational needs.

**Participant type(s)**

Patient

**Age group**

Child

**Sex**

Both

**Target number of participants**

99

**Key exclusion criteria**

Not provided at time of registration

**Date of first enrolment**

01/01/1996

**Date of final enrolment**

31/12/1999

## Locations

**Countries of recruitment**

England

United Kingdom

**Study participating centre**

Greenwood Institute of Child Health

Leicester

United Kingdom

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## Sponsor information

**Organisation**

Record Provided by the NHS R&D 'Time-Limited' National Programme Register - Department of Health (UK)

**Sponsor details**

The Department of Health

Richmond House

79 Whitehall

London

United Kingdom

SW1A 2NL

**Sponsor type**

Government

**Website**

<http://www.doh.gov.uk>

## Funder(s)

**Funder type**

Government

**Funder Name**

NHS Mother and Child Health National Research and Development Programme (UK)

## Results and Publications

**Publication and dissemination plan**

Not provided at time of registration

**Intention to publish date****Individual participant data (IPD) sharing plan****IPD sharing plan summary**

Not provided at time of registration

**Study outputs**

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<a href="#">Results article</a>	Results	28/06/2008		Yes	No