

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

Dr John Moore

Contact details

Greenwood Institute of Child Health

University of Leicester

Westcotes Drive

Leicester

United Kingdom

LE3 0JU

+44 (0)116 225 2880

johnmoore11@doctors.org.uk

Additional identifiers

Protocol serial number

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

Study type(s)

Quality of life

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(s)

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.

Key secondary outcome(s)

Not provided at time of registration

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

Healthy volunteers allowed

No

Age group

Child

Sex

All

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

United Kingdom

England

Study participating centre

Greenwood Institute of Child Health
Leicester
United Kingdom
LE3 0JU

Sponsor information

Organisation

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

Funder(s)

Funder type

Government

Funder Name

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

Results and Publications

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?
Results article	Results	28/06/2008		Yes	No