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The effectiveness of a parent-held record for disabled children

Submission date	Recruitment status	[_] Prospectively registered
23/01/2004	No longer recruiting	[_] Protocol
Registration date	**Overall study status**	[_] Statistical analysis plan
23/01/2004	Completed	[X] Results
Last Edited	**Condition category**	[_] Individual participant data
22/02/2008	Mental and Behavioural Disorders	

Plain English summary of protocol
Not provided at time of registration

Contact information

Type(s)
Scientific

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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

Primary study design
Interventional

Study design
Randomised controlled trial

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
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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