

Experiences with Care Co-ordination among People with Cerebral Palsy, Multiple Sclerosis, or Spinal Cord Injury

Purpose: To describe the experiences with care co-ordination of people with cerebral palsy, multiple sclerosis, or spinal cord injury; to determine barriers to effective care co-ordination; and to compare experiences across disability and health plan types.

Methods: Qualitative, semi-structured telephone interviews with 30 people with cerebral palsy, multiple sclerosis, or spinal cord injury. Interviews focused on the care co-ordination experience of individuals in managed care and traditional indemnity health insurance plans in the USA and were analysed using NVivo.

Results: Half of the respondents reported that they had a health professional who co-ordinated their care. Participants identified barriers that prevented effective care co-ordination, including a lack of disability specific knowledge, providers' limited time and effort related to care, and insufficient communication among providers. There were few differences between managed care and fee-for-service respondents with regard to these barriers.

Conclusions: Study findings reveal few differences in the care co-ordination experiences amongst people with cerebral palsy, multiple sclerosis, or spinal cord injury in both plan types. All providers need to become more literate about the health care needs of people with physical disabilities, and health plans need to reward communication among providers and the time and effort invested in care co-ordination.

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