

Evaluation of the Role of Advocacy and the Quality of Care in Reducing Health Inequalities for People with Autism, Intellectual and Developmental Disabilities at Sheffield Teaching Hospitals

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Abstract : Individuals with Autism, Intellectual and Developmental disabilities (AIDD) are one of the most vulnerable groups in society, hampered not only by their own limitations to understand and interact with the wider society, but also societal limitations in perception and understanding. Communication to express their needs and wishes is fundamental to enable such individuals to live and prosper in society. This research project was designed as an organisational case study, in a large secondary health care hospital within the National Health Service (NHS), to assess the quality of care provided to people with AIDD and to review the role of advocacy to reduce health inequalities in these individuals. Methods: The research methodology adopted was as an "insider researcher". Data collection included both quantitative and qualitative data i.e. a mixed method approach. A semi-structured interview schedule was designed and used to obtain qualitative and quantitative primary data from a wide range of interdisciplinary frontline health care workers to assess their understanding and awareness of systems, processes and evidence based practice to offer a quality service to people with AIDD. Secondary data were obtained from sources within the organisation, in keeping with "Case Study" as a primary method, and organisational performance data were then compared against national benchmarking standards. Further data sources were accessed to help evaluate the effectiveness of different types of advocacy that were present in the organisation. This was gauged by measures of user and carer experience in the form of retrospective survey analysis, incidents and complaints. Results: Secondary data demonstrate near compliance of the Organisation with the current national benchmarking standard (Monitor Compliance Framework). However, primary data demonstrate poor knowledge of the Mental Capacity Act 2005, poor knowledge of organisational systems, processes and evidence based practice applied for people with AIDD. In addition there was poor knowledge and awareness of frontline health care workers of advocacy and advocacy schemes for this group. Conclusions: A significant amount of work needs to be undertaken to improve the quality of care delivered to individuals with AIDD. An operational strategy promoting the widespread dissemination of information may not be the best approach to deliver quality care and optimal patient experience and patient advocacy. In addition, a more robust set of standards, with appropriate metrics, needs to be developed to assess organisational performance which will stand the test of professional and public scrutiny.

Keywords : advocacy, autism, health inequalities, intellectual developmental disabilities, quality of care

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