

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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I. INTRODUCTION

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—Autism, intellectual developmental disabilities, advocacy, health inequalities, quality of care.

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IT is well recognised that individuals with AIDD remain one of the most vulnerable and socially excluded groups [1]-[5]. Legislation in the UK, in the form of the Equality Act 2010 [6], the Autism Act 2009 [7], the Care Act 2014 [18], and the Human Rights Act [8], clearly state that all individuals, irrespective of age, sex, ethnicity, religion or disability must be supported in their access to health care and with equal rights. The Acts refer to all aspects of life including health and social care. The Equality Act 2010 [6] introduced the concept of “*reasonable adjustments*” to be applied to individuals with protected characteristics under the act, of which one is ‘disability’. Flynn [9] suggests that this could be considered “national” or “systemic” advocacy. This research project sets out the findings of an inquiry into advocacy at Sheffield Teaching Hospitals NHS Trust (STH) to identify if its current compliance with relevant advocacy and associated legislation indicates evidence of quality of service provided to people with AIDD.

People with AIDD often have significant communication difficulties [10], [11]. Interaction, therefore, may well require a level of personalisation in communication methods between service providers and the person and their family [12]-[14]. Advocacy is a concept that has been developed to support the enablement of communication methods and is particularly important when people with AIDD encounter new situations and new environments. Gray and Jackson [15] define advocacy as a “right to a voice” whereas the Citizen’s Information Centre [16] is more emphatic, deliberate and challenging by defining this as “a process of empowerment”. The concept and foundations of advocacy are well established; its potential role for individuals who lack capacity, independence, self-determination and self-realisation [17] is undisputed; but its uptake, legal foundation and acceptance by wider society are less clear. The Care Act [18] introduced a new type of advocacy called ‘independent advocacy’. This form of advocacy, for the first time, accepted that the person with AIDD and their family needed support by an independent person to enable the facilitation of communication and to advocate for the right services to meet the person’s needs. The importance of advocacy is reiterated by the recent service model guidance for commissioners for health and social care from NHS England [19], which states:

“At key points in their interaction with health, education and care services, people with a learning disability and/or autism who have a mental health condition or display behaviour that challenges should have access to different types of independent advocacy. In addition to the legal right to advocacy, people should also be offered non-statutory advocacy, which should be available to them either at key transition points and/or for as long as they require at other times in their lives. This will include in preparation for and on leaving a specialist hospital. Both statutory and non-statutory advocacy should be delivered by services that are independent of the organisations providing the person’s care and support.”

The objective of this research project was to undertake a critical inquiry at the application and impact of advocacy for individuals with AIDD within an acute hospital setting. Paternalism, manifest as professional advocacy, however decried as the “antithesis of autonomy” [20], exists and remains a major factor in decision making within the health care sector. Mencap [21] describes this as “flawed best interest decision-making”. Attempts to broaden the types of support for individuals with AIDD have, therefore, been limited by an inability to envision a system which values autocracy and control.

II. METHODS

The research project was designed as an organisational case study [22], [23] assessing two specific, but related, aspects of organisational strategy for providing care for individuals with AIDD. Using a constructionist paradigm the first part of the study gathered secondary data from the organisation, patients with AIDD and their families and carers, including patient survey data, incidents and complaints, to assess and analyse the systems and processes that have been put in place, in line with the published national standards [24]. The second part of the study collected primary data to assess the impact of knowledge and dissemination of information [25] to front line staff caring for individuals with AIDD.

The research question regarding the role of advocacy and the quality of care in reducing health inequalities for people with AIDD at Sheffield Teaching Hospitals, required both qualitative and quantitative data in response to related questions, with the aim of triangulating and complementing data [26], [27] i.e. a mixed methods research process [28]-[31]. The priority of the research strategy was the qualitative data with integration of the quantitative data at analysis, the so-called “concurrent nested strategy” [31], [32]. Qualitative data included secondary data from the Organisation and primary data in the form of a semi-structured interview. Organisational data were obtained from the Learning Disability (LD) Lead for the Organisation and from the Organisations intranet web site. Annual LD reports were also present in the public domain and obtained through a standard search engine (Google). The last Annual LD Report (2015-16) was present in draft form and obtained, by request, from the LD Lead for the Organisation.

A semi-structured questionnaire was used to guide the interview. This is a technique commonly used in healthcare research [33]-[37] to delve and explore key ideas and themes [38]. The questionnaire was designed to enhance the “quality” of the qualitative data obtained from participants. The questions were grouped into three sections exploring the participants’ knowledge and awareness of:

1. AIDD services within the Organisation and
2. Advocacy and advocacy services

Certain ethical considerations were taken into account to ensure validity of the data collection [31]:

1. Participants from all healthcare groups were approached to minimise sampling bias [39];
2. All the participants were voluntary;
3. Participants were informed of the purpose of the study and the potential outcomes and were given a copy of the participant information sheet and consent;
4. Participants were informed that all the data would be anonymised and kept in a safe and secure site;
5. Participants were informed that they had a right to a copy of the results.

The interviews were carried out in a quiet neutral office, avoiding distraction and ensuring equanimity between the interviewer (JS) and the participant [40]. The format and length of the interview was explained. The participants were asked if the interview could be recorded. Contact information was given if the participants had any questions, queries or concerns. The interviews were transcribed by an independent medical secretary and a “rich” summary is obtained using the interview questions as a framework for the answers.

III. DATA ANALYSIS

The qualitative secondary data from the Organisation were analysed in a thematic way using constant comparison analysis [41] against the Monitor Compliance Framework standards. The primary data from the staff interviews were analysed using a sequential mixed analysis approach [42] with priority given to the qualitative data [43]. The latter was analysed in a thematic fashion with subsequent quantitative integration [44].

IV. RELIABILITY AND VALIDITY

“Practitioner enquiry” [45] or “insider research” [46], [47] raises a number of concerns about ethics, the lack of objectivity [48]-[51] and the biases that may be inherent to this particular methodology [52]. As a consequence, the reliability and validity of the research findings [40], [53] is subjected to reflexivity [78] as a quality assurance mechanism considered of value to qualitative research. This can be described as “trustworthiness in research” [54]. Guba [55] puts forward four criteria to assess the trustworthiness of research:

1. Credibility
2. Transferability
3. Dependability
4. Confirmability

Credibility and dependability would translate to maintaining

objectivity and eliminating bias. Transferability and confirmability could be demonstrated by a larger scale study within the Organisation or a parallel study in another

secondary healthcare organisation. Table I is a critical assessment of the validity of the research method, methodology and data analysis used for this project:

TABLE I
RELIABILITY AND VALIDITY OF RESEARCH PROJECT

Criteria	Evidence to support impartiality
Objectivity	Objectivity maintained by partial insider role [77]
Duality of role	Subject matter in a different field of interest Minimal contact with the organisation as a carer and advocate
Bias	Topic of interest to me but removed from area of work and no contact with the Organisation as a carer/user
Topic	
Questions	Questions focused on individual knowledge and awareness of the Mental Capacity Act 2005, AIDD services and advocacy types and services. The questions were designed pre-study to allow for exploration and discussion with participants
Participants/participant behaviour	Participants were asked to speak freely and were informed that they were not being tested and there were no right or wrong answers
Access	No favourable access obtained for interview participants although my role within the Organisation allowed me to approach individuals more freely
Power	Participants were informed that a researcher from within the department should not be viewed as a member of staff
Data collection	All Annual LD reports, including commissioned reports such as Pickering Institute report (Appendix A), are available to the public
Access to documents	As per access above
Semi-structured interview and access to participants	
Analysis and reporting	Secondary data regarding Organisational performance, produced independently, underwent comparative thematic analysis with a nationally-derived framework (Monitor compliance framework) Primary data from the semi-structured interview underwent thematic analysis with pre-determined themes
Ethical issues	Participants from all healthcare groups were approached to minimise sampling bias [39]
Honesty and integrity	All the participants were voluntary
Privacy	Participants were informed of the purpose of the study and the potential outcomes and were given a copy of the participant information sheet and consent;
Responsibility	Participants were informed that all the data would be anonymised and kept in a safe and secure site Participants were informed of their right to a copy of the results

V. RESULTS

The results are presented in two parts:

Part 1: Secondary qualitative data drawing upon a framework for a 'case study' using patient survey feedback and patients complaints

Part 2: Primary qualitative and quantitative data gathered from front line staff interviews

A. Part 1

1. Assessment of Organisational Performance in Providing AIDD Services

The first part of this research project looked at the overall Organisational performance against the published quality standard for secondary health care organisations, The Monitor Compliance Framework is derived from the recommendations from Michael (24). Table II is taken from the Sheffield Teaching Hospitals Foundation Trust Learning Disability Annual Report 2015-16 [79], and demonstrates Organisational "compliance" in five out of the six criteria. A Carers Strategy [80] is being developed to achieve "compliance" with the 3rd criteria.

2. Learning Disability Patient Survey

The patient survey, commissioned by Sheffield Teaching Hospitals Charitable Trust, was conducted between February 2015 and July 2015, by the Pickering Institute, Europe. The survey was carried out on inpatients and day cases and consisted of 10 questions exploring their experience in the hospital. The results are presented below with a comparative analysis of historical patient survey data from Leeds Teaching

Hospitals (2013) [81], the 2015 National Adult Inpatient Survey [82] and the Department of Health "Six Lives" report from 2013 [83]. 300 surveys were mailed to patients with LD and their carers. 108 (36%) were completed.

- i. Did you understand what the doctors and nurses said? In the Sheffield patient survey 59% of respondents indicated that they had understood the doctors and nurses. In the Leeds survey 55% of respondents answered affirmatively. The corresponding figures for the National survey was 72% and for the "Six Lives" report, 54%.
- ii. Did the doctors and nurses listen to you? In the Sheffield survey 75% of respondents indicated that the staff had listened to them. In the Leeds survey only 60% stated that this was the case. The corresponding number in the "Six Lives" report was 84%, which included a composite of "always listening" and "sometimes listening" to the LD individual, family or carer.
- iii. Did you get to talk to the doctor or nurse? The vast majority (89%) of respondents in the Sheffield and Leeds patient surveys (89% vs. 81% respectively) stated that they had been able to communicate with the doctor or nurse. However, in the "Six Lives" report, this only occurred in 40% of individuals and 44% of family and carers.
- iv. Did staff tell you enough about your operation? 89% of respondents in the Sheffield survey said "yes" whereas only 54% said "yes" in the Leeds survey and 77% said "yes" in the National survey.
- v. Did you get help eating and drinking? In the Sheffield survey 68% of respondents said "yes". In the National

survey this figure was slightly higher at 72 %.

TABLE II
MONITOR COMPLIANCE FRAMEWORK

Criteria	Evidence/Compliance
1. The Trust has a mechanism in place to identify and flag patients with LD and protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients	Lorenzo flagging system (new patient administration system replacing PAS) linked to Sheffield Health and Social care LD Case Register (shsc.nhs.uk/service/case-register) <i>LD alert system (accessed through LD intranet site via Admission and Discharge advice site)</i> Equality, diversity and human rights strategy (access via STHFT LD intranet site). Learning disability link staff (accessed via LD intranet site). Admission/discharge algorithms (accessed via Trust LD intranet site) Compliance: YES
2. The Trust provides readily available and comprehensible information to patients with LD about treatment options, complaints procedures and appointment	Intranet resources include – Easy read library Easy read complaints leaflet (Available on the Trust LD intranet site) Compliance: YES
3. The Trust has protocols in place to provide suitable support for families/carers that support patients with LD	LD nursing care guidelines (accessed through the Trust LD intranet site under Admissions and Discharge advice) Compliance: PARTIAL
4. The Trust has protocols in place to routinely include training on providing health care to patients with LD for all staff	E-learning GMC LD – accessed via LD intranet site E-learning LD – accessed via Trust LD intranet site. E-learning Hidden Impairments PROUD values used within appraisal process. “Prepare to Care” courses includes LD presentation (correspondence from learning and Development team at STH – 12 courses a year aimed at Care Support Workers (CSW). Presentations include: Duty of Care, Equality and Diversity, Communication, Privacy and Dignity, Awareness of Mental health, Dementia and Learning Disability. In 2015-2016 166 CSWs went through the programme. The programme enables CSWs to obtain a Care Certificate. “Well-being study days” (Sheffield Wellbeing Feasibility Study presented at European Public Health Conference, Glasgow Nov 20 th 2014) Compliance: YES
5. The Trust has protocols in place to encourage representation of people with LD and their families/carers	Disability user groups within the Trust e.g. Ophthalmology and Radiology Department at Weston Park Hospital Trust has volunteers with LD Nurse Director represents the Trust on LD Partnership Board; ND has done presentations at Carer forums and listened to their views/concerns. Compliance: YES
6. The Trust has protocols in place to regularly audit its practices for patients with LD and to demonstrate the findings in routine public reports	Carer Audit 2010 Patients survey completed Compliance: YES

- vi. Were you ever in pain? In the Sheffield and Leeds surveys, 53% and 63%, respectively, indicated that they had been in pain.
- vii. Did you get help to stop your pain? In the Sheffield survey 79% of individuals, families and carers said that had been given help to stop their pain. The corresponding percentages in the Leeds and National surveys, and the “Six Lives” report were 73%, 72% and 40% respectively.
- viii. Discharge – did staff tell you what to do? 84% and 60% of respondents indicated “yes” in the Sheffield and Leeds surveys respectively.
- ix. How well were you looked after? In the Sheffield survey 73% of individuals or their families or carers said they were looked after “very well”. In the Leeds and National cohorts the corresponding figures were 54% and 83%. In the “Six Lives” report 46% of individuals with LD and 38% of carers said that they had been looked after “very well”.
- x. Were you ever treated unfairly? In the Sheffield survey 79% of respondents said “no”. In the Leeds survey 80% said “no”, but 9% said that they were treated unfairly. In the “Six Lives” report 62% of individuals with LD said that they were shown respect, whereas only 44% of families and carers felt that the individual with LD was shown respect.

B. Part 2

1. Staff Interview

A semi-structured interview was carried out with 21 members of staff within the Organisation. 20% of the participants were physicians. The remainder of the participants was either nursing staff or support staff. Table III is a breakdown of the staff that was included in the study.

The interview questions were broken down into 3 thematic groups: A. Knowledge and understanding of the Mental Capacity Act (2005); B. Organisational care of individuals with AIDD; C. Advocacy and advocacy services.

TABLE III
PARTICIPANTS IN STAFF SURVEY

Participant (Code)	Number
Health care assistant (HC1, HC2)	2
“Hotel” staff (H1)	1
Nursing staff (N)	14
Staff nurses (NS 1-5)	5
Sisters/Charge nurses (NC 1-7)	7
Matrons (NM 1, NM2)	2
Physicians (P)	4
Junior doctors (PD1)	1
Middle grade doctors (PR1)	1
Consultants (PC 1 and PC2)	2

C. Knowledge and Understanding of the Mental Capacity Act (2005)

The first two questions in the staff interview related to the MCA (2005): the statutory principles of the Act and the associated Code of Practice.

Only 1 out of the 21 participants (NC4) knew the statutory principles and to which groups the Code of Practice referred to. None of the senior physicians interviewed (PR1, PC1 and PC2) could quote the principles. However, the most junior physician (PD1) stressed one of the guiding principles to aid individuals as much as possible to enable decision-making. There was a general understanding amongst the physicians of the concept of capacity and how to determine the lack of capacity. Only 1 out of the 4 physicians (25%) (PR1) could name any one of the groups of people to whom the Code of Practice referred to. Three members of the nursing staff (21%) (NC4, NC7, and NM1) were able to indicate one of the groups of individuals to whom the Code of Practice covered. One additional member of the nursing staff (7%) (NC2) said that they would access the information on the Trust intranet site.

D. Organisational Care of Individuals with AIDD

The next series of questions referred to the care of patients with AIDD. More specifically questions were raised about: a) registering of individuals with AIDD; b) resources available within the Organisation to be able to interact with individuals with AIDD (the example given was an AIDD patient with serious communication difficulty); c) training and mentoring for staff involved in caring for individuals with AIDD; d) awareness of LD liaison nurses; e) the Lead for LD within the Organisation; f) whether families and carers were included in provision of care and treatment and g) awareness of social, cultural and spiritual issues when caring for individuals with AIDD.

All of the physician participants hoped that there was some system in place to register individuals with AIDD but they were not sure if this was the case. Only one out of four physicians (25%) was aware of some of the resources available to communicate with individuals with severe communication problems. All of the physicians were aware of any some type of training: There was no knowledge of any type of mentoring, LD link or liaison nurses or the LD Lead within the Organisation. All the physicians felt that families and carers were adequately involved in the provision of treatment and care. With regard to social, cultural and spiritual issues, only 1 out of the 4 physicians (25%) felt that they were sufficiently prepared in general.

Of the nursing and ancillary staff, 30% (NC3, NC4, NC7, NM1 and NM2) were aware of the specifics and importance of registering individuals with AIDD. Three out of the 17 nursing and ancillary participants (18%) stated that this was documented in the medical notes and one out of the 17 participants (NC1) "hoped" that there was some form of documentation for individuals with AIDD. 66% of the nursing and ancillary staff had knowledge of, and had used, particular resources to interact with individuals with communication difficulties (H1, NS3, NS4, NS5, NC3, NC4, NC5, NC6, NC7,

NM1 and NM2). 24% of the nursing and ancillary group (NS4, NC4, NC6, NC7) were aware of training support through the Trust intranet and two out of 17 (12%) (NS3 and NC1) commented upon training study days. 6% of the nursing and ancillary group was aware that mentoring was available. 33% of the nursing group (senior nursing staff) was aware of the LD links within the Organisation. None of the nursing group knew of any LD liaison nurses. Only two members of the nursing and ancillary staff (12%) knew the name of the Lead for LD.

The final two questions were more open-ended. Only one out of 17 nursing and ancillary staff (6%) (NS4) felt that they did not use families or carers enough in the treatment and provision of care. Two out of the 17 (NC4 and NM2) participants in the nursing and ancillary group (12%) said there was some differential treatment: "for younger patients we use their family, more so than in older people" (NM2). The remaining 14 participants (84%) indicated quite clearly that they felt they included family members and carers in decision-making and delivering care. Seven out of the 17 nursing and ancillary staff (42%) (HC1, NS4, NS5, NC1, NC4, NC5 and NC6) did not feel adequately trained or "prepared" to deal with any social, cultural and spiritual issues within this group of patients. An additional 2 out of 17 (12%) nursing and ancillary staff (NM1 and NM2) said that they felt this was very variable and dependent upon the staff member.

E. Advocacy and Advocacy Services

The final set of questions referred directly to advocacy and provision of advocacy services within the Organisation. The first 2 related questions were to describe the role of an advocate and expectation of advocacy services by users of these services i.e. health care professionals. The next series of questions asked participants to define the types of advocacy that were available for health care professionals working in the Organisation, the Code of Practice, the funding arrangements and the auditing process for advocacy? If the IMCA service was not volunteered by the participants, then it was brought up as an additional question.

All of the participants responded in a positive and affirmative manner to the question regarding role of an advocate and their expectations as users of advocacy services. Comments included: "the best interests of the patient" (NS2, NC1, NC4, PC1); "to stand up for the patient's rights" (NS2, NS5); "to support patients' rights to decisions" (NS4, NC7, NM1); "independent voice for the person" (NM2). In contrast, the range of responses was quite wide when asked about the types of advocacy. Of the physician participants, 25% (PC1) talked about professional advocates (although that term was not used) in the form of nursing staff. 25% (PD1) mentioned family members or next of kin and 75% (PD1, PR1, PC1) mentioned the IMCA service.

In a similar way, the nursing and ancillary staff respondents varied from 42% not being aware of any types of advocacy, to 24% (HC2, NS5, NC5, NM2) describing professional advocates in the form of physicians or nurses. 18% of the nursing and ancillary group participants (HC1, HC2, NC7)

referred to family members and carers as advocate. Only one member of this group (NS4) mentioned the LD link person as an advocate. However, 5 out of 17 (30%) (NC4, NC5, NC6, NM1 and NM2) mentioned the IMCA service. The remainder of the questions was poorly answered by all the participants including accessing the IMCA service and the specific role of the IMCA.

VI. DISCUSSION

As described in the methods section, the study has been designed as a case study [22], [23] looking at the performance of Sheffield Teaching Hospitals in providing health care for individuals with AIDD, with particular emphasis on advocacy. Although the study has been conducted in 2 parts, the results are presented as a “continuum” i.e. “macrosystem” data in the form of the Organisational data, “mesosystem” data, looking at internal processes [56] in the form of the staff survey results, and finally “microsystem” data [57] in the form of the results of the patient survey. If one were to simply focus on one level of data, for example, the Organisational data in relation to the Monitor Compliance Framework, then the Organisation would appear to be performing well. One could argue that blind acceptance of a single piece of data such as this, may hamper, slow down or even stop ongoing learning, change and development and ultimately affect improvement of services for individuals with AIDD. The staff survey results highlight significant issues with regard to the knowledge and understanding of the Mental Capacity Act (2005), awareness of protocols and processes involved in the day-to-day care of individuals with AIDD and poor awareness of the range of advocacy services available for individuals with AIDD.

The final piece of data is the patient survey, taken from STHFT LD Annual Report 2015-16. The questions posed in the survey were somewhat limited in comparison to the “Six Lives” survey report [58]. Notwithstanding this fact, there certainly appears to be a degree of congruence between findings and concerns have to be raised about communication with individuals with AIDD, poor understanding of individuals with AIDD and a lack of reasonable adjustments that are made.

If one considers all of these pieces of information, then in answer to the question: “What is the overall Organisational performance in providing health care for individuals with AIDD?”, then one would have to conclude that the Organisation has performed poorly.

VII. LIMITATIONS OF THE RESEARCH

The semi-structured staff interview was designed to explore their understanding and knowledge of the Mental Capacity Act (2005), LD services within the Organisation and the range of advocacy services available to them. Three limitations need to be highlighted:

1. The small sample size.
2. The interviewed staff members were from one part of the Organisation.
3. The mix of participants was uneven.

The sample size and the group that was selected were meant to be representative of a typical large acute secondary health care organisation. The exclusion of staff groups that dealt with “brain injury”, such as Neurology, Neurosurgical services or Spinal Injuries, or Mental Health services was intentional on the premise that they would have a skewed and unrepresentative knowledge base and understanding of mental capacity, learning disability and advocacy services. A larger all-inclusive survey may well highlight, in rather a stark way, the differences in understanding, knowledge and access to particular services for individuals lacking mental capacity, by different groups within the Organisation.

The Methods section should include equal numbers of staff from the various health care groups. This has not been the case. However, the uneven distribution reflects, in a more accurate way, the complement of staff groups within a secondary care organisation.

A. Organisational Strategy to Improve Lives and Health for Individuals with AIDD

The number of individuals with AIDD continues to rise with the result that there will be ever increasing demands on public services such as education, health and social care. This section will discuss and propose strategies to improve the quality of healthcare for individuals with AIDD.

Organisational strategy can be broken down and analysed by looking at the context, strategic purpose, choices and development [59]. The context is the well documented health inequalities in the form of increased and premature mortality and increased morbidity [3], [24], [60]-[66] Addressing these inequalities in health forms the basis of the strategic purpose for the Organisation. In the wider context this will not only require a change in societal values and perception but, more directly, from an organisational point of view, improved services in both primary and secondary care. Johnson et al. [59] describe two diametrically opposite choices in the form of either a competitive strategy or a cooperative strategy. Philosophically, economically and from an efficiency point of view, a cooperative and collaborative strategy, with the Organisation working with primary healthcare, social care services and third sector organisations, would be the most appropriate choice of strategic model.

Strategy development has a number of elements including identification of resources, implementation of care pathways and defining performance metrics. This small research project has been able to demonstrate a wide chasm between policies, proposals and recommendations made at both national and local levels and their implementation and delivery, the so-called “second translation gap” [67]. One of the factors which may affect implementation is the dissemination of knowledge and information, both explicit and tacit [68], [69] within a large organisation. The staff and patient survey has shown that our current information-technology based systems, to educate and make staff aware of critical knowledge such as the Mental Capacity Act (2005), protocols and processes have only been partially successful. There is growing evidence of the key role of LD liaison nurses/acute liaison teams [70]-[72] in bridging

this gap and providing effective, efficient care and support for individuals with AIDD together with supporting staff. Brown [72] cites the contributions made by LD liaison nurses (Table IV).

TABLE IV
CONTRIBUTIONS OF LD LIAISON NURSES

Contribution of LDLN service	Number of stakeholder comments on each contribution
Co-ordinating care (care co-ordination, discharge planning, pre-admission planning)	105
Promoting successful communication	51
Taking the pressure off	47
Facilitating reasonable adjustments	44
Preventing poor outcomes	29
Improving patient experience	26
Ensuring adherence to capacity legislation	16

The stakeholders in the study included individuals with LD, carers, primary and secondary health professionals and LD liaison nurses. A Mencap report in November 2014 [73],

following a freedom of information request to 165 NHS Acute Hospital Trusts, stated that 42% of Acute Trusts did not have any LD liaison nurses. This appears to be the case for Sheffield Teaching Hospitals.

The initial part of the research project was to look at the Organisational performance in relationship to the current quality standard (Monitor Compliance Framework). This paper has criticised the current standard and has suggested that a more inclusive and robust framework, with appropriate metrics, is required for monitoring overall Organisational performance. We can draw upon the Health Self-Assessment Framework, produced as a guide for commissioners [74], to formulate a more comprehensive and inclusive set of quality standards. Table V, adapted from Kaplan [56], outlines the important indicators within the three domains of customers and patients, internal processes and organisational learning, and proposes particular metrics that could be used to assess and monitor quality standards for secondary care organisations. The proposed scorecard incorporates criteria from the Secondary Care Charter for LD [75].

TABLE V
PROPOSED SECONDARY CARE ORGANISATIONAL PERFORMANCE SCORECARD FOR AIDD

Domains/KPI	Metrics
Customer/patient	
Display "Getting it Right" principle	90% compliance
Individual Hospital Passport	90% compliance
Provide appropriate information	5-point Likert scale
Listen, respect and involve individuals family and carers	Subjective: Likert scale
Audit of experiences	Objective: numbers of individuals with AIDD on patient forums as a % of numbers of forums
Internal processes	Percentage of individuals with AIDD who participated in annual surveys
Register individuals with AIDD	90% compliance
Demonstrate safeguarding arrangements	Stories and case studies
Appropriate advocacy systems, processes and quality standards (QPM for IMCA service)	Percentage of AIDD individuals/carers/AIDD liaison nurses accessing advocacy services.
Protocols and pathways demonstrating "reasonable adjustments"	QPM for IMCA service.
Demonstration of integration of care and assessment of needs	Stories and case studies/patient survey
Organisational learning	Percentage of individuals with AIDD with a health plan as a proportion of total
Enactment and monitoring of MCA 2005	90% compliance (e-learning)
Education, training and support for staff	Courses and attendance by groups as % of total
Audit and production of annual reports	90% compliance
Audit of outcome measures	Mortality data
	Morbidity data
	Outpatient attendance
	Inpatient length of stay
	Patient survey/stories
Audit of experience measures	5-point Likert scale

TABLE VI
PROPOSED LD ORGANISATIONAL STRATEGY

Organisational strategy	Process and outcome
Context	Increased mortality and morbidity Poor patient and carer experience Poor staff awareness and understanding Reduce health inequalities
Purpose	Improve patient and carer experience Improve staff awareness and understanding
Choice	Cooperative/collaborative approach with primary healthcare services, social care, MENCAP, BILD, local voluntary advocacy organisations, patient and carer. Aim to develop efficient and effective integrated care pathways
Development	Improve education within the Organisation Improve knowledge management systems Develop AIDD Liaison Nurse Specialist service/AIDD Liaison specialist team Devise a robust auditable performance scorecard

There will be increasing scrutiny of Organisations and Trusts, and their governance arrangements, following critical reports such as the Care Quality Commission report on the failures of the Southern Health NHS Foundation Trust to maintain the safety of individuals within their mental health and learning disability services [76]. The major findings from the report were:

1. Very few unexpected deaths amongst individuals with LD and individuals over the age of 65 years with mental health problems were investigated (only 4 out of 93 (4%) deaths in individuals with LD were investigated);
2. In 64% of investigations families were not involved;
3. The trust failed to use their data from the deaths;
4. There was no robust system in place to learn from their deaths.

The Secretary of State for Health, the Right Honourable Jeremy Hunt MP, in his statement to the House of Commons at the time of the publication of the report [76], stressed the importance of building "a culture in which failings in care from the basis for learning for organisations and for the system as a whole". Although the statement focused on issues related to mortality it is equally important, if not more important, to widen the focus to scrutinise and improve all aspects of health and social care support and delivery to vulnerable groups such as individuals with AIDD and mental health problems. Healthcare Trusts and social care services need to develop and implement robust and transparent systems to ensure high quality care, auditing processes and clear systems demonstrating organisational learning to continually improve care. Family and carer involvement in the design and delivery of care is paramount.

VIII. CONCLUSIONS

Individuals with AIDD remain one of the most vulnerable groups of people in society, often ignored and marginalised by society. Attitudes towards such individuals are changing slowly with help from various organisations such as MENCAP and BILD. Advocacy for individuals with AIDD is the foundation by which we as a society start to understand and provide adequate support and care for such individuals.

Health inequalities endured and suffered by individuals with AIDD are profound and disturbing. Addressing these inequalities will require continued changes in societal attitudes and values and significant improvements in the quality of healthcare, social care and public services. This organisational case study has looked at the quality of AIDD and advocacy services in a large acute secondary healthcare organisation. The findings have demonstrated poor organisational performance if one takes into consideration data from staff and patients. The awareness of the different types of advocacy available was very poor amongst the representative staff group. A significant amount of work needs to be undertaken to improve the quality of care delivered. A strong argument can be made for specialist teams with the expertise and skills to liaise with individuals with AIDD, their families and carers to improve experience, promote advocacy and deliver quality care. In addition, organisations will be accountable for the

quality of service that is provided with both public and professional scrutiny. Robust systems and processes need to be developed by organisations to demonstrate quality care and willingness of the Organisation to learn and develop.

REFERENCES

- [1] Department of Health. "Valuing People. A new strategy for learning disability for the 21st century". March 2001.
- [2] Department of Health. "Valuing People Now: A New Three Year Strategy for People with Learning Disabilities." 2009.
- [3] Mencap. "Death by indifference." *London, Mencap* 2007.
- [4] A. Lawton. "Personalisation and Learning Disabilities: A review of evidence on advocacy and its practice for people with learning disabilities and high support needs." *London: SCIE* 2009.
- [5] M. Flynn. "Winterbourne View Hospital: a serious case review." *South Gloucestershire Safeguarding Adults Board* 2012.
- [6] HMSO. Equality Act 2010.
- [7] HMSO. Autism Act 2009
- [8] HMSO. Human Rights Act 1998
- [9] E. Flynn. "A socio-legal analysis of advocacy for people with disabilities—competing concepts of 'best interests' and empowerment in legislation and policy on statutory advocacy services." *Journal of social welfare & family law*, 2010. **32** (1), 23-36.
- [10] A. Gaag. "Communication skills and adults with learning disabilities: eliminating professional myopia." *British Journal of Learning Disabilities* 26.3 1998: 88-93.
- [11] J. Jones. "A total communication approach towards meeting the communication needs of people with learning disabilities." *Tizard Learning Disability Review* 5.1 2000: 20-26.
- [12] American Speech-Language-Hearing Association. "Definitions of communication disorders and variations." 1993.
- [13] Kress, Jeffrey S., and Maurice J. Elias. "Substance abuse prevention in special education populations: Review and recommendations." *The Journal of Special Education* 27.1 1993: 35-51.
- [14] H. Bradley. "Assessing and Developing Successful Communication". *People with Profound & Multiple Learning Disabilities: A Collaborative Approach to Meeting*. Routledge , 2013.
- [15] B. Gray, R. Jackson. *Advocacy and Learning Disability*. Jessica Kingsley Publishers, 2002.
- [16] Citizen Information Centre, 2001
- [17] M. Wullink et al. "Autonomy in Relation to Health among People with Intellectual Disability: A Literature Review." *Journal of Intellectual Disability Research* 53.9 2009: 816-26.
- [18] HMSO. Care Act 2014.
- [19] NHS England. *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*. London, NHS England. 2015.
- [20] B. J. Pollard. "Autonomy and Paternalism in Medicine." *The Medical Journal of Australia* 159.11-12 (1993): 797-802.
- [21] Mencap. "Death by Indifference. 74 Deaths and Counting." Mencap 2012.
- [22] R. K. Yin. *Case Study Research: Design and Methods*. 5 Vol. Sage Publications, Incorporated, 2008.
- [23] P. Baxter, S. Jack. Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, 2008. 13 (4), p.p.544-559.
- [24] J. Michael, A. Richardson. "Healthcare for all: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities." *Tizard Learning Disability Review* 13.4 2008: 28-34.
- [25] M. Exworthy, L. Berney, M. Powell. "'How Great Expectations in Westminster may be Dashed Locally': The Local Implementation of National Policy on Health Inequalities." *Policy & Politics* 30.1 2002: 79-96.
- [26] N. K. Denzin. *The Research Act: A Theoretical Introduction to Sociological Methods*. Transaction publishers, 1973.
- [27] J. C. Greene, V.J. Caracelli, W.F. Graham. "Toward a Conceptual Framework for Mixed-Method Evaluation Designs." *Educational evaluation and policy analysis* 11.3 1989: 255-74.
- [28] J. W. Creswell. "Research Design: Qualitative, Quantitative, and Mixed Methods Approaches." 2003.
- [29] R. B. Johnson, A.J. Onwuegbuzie. "Mixed Methods Research: A Research Paradigm Whose Time has Come." *Educational researcher*

- 33.7 (2004): 14-26.
- [30] J. Mason. "Six Strategies for Mixing Methods and Linking Data in Social Science Research." 2006.
- [31] S. R. Terrell. "Mixed-Methods Research Methodologies." *The Qualitative Report* 17.1. 2012: 254-80.
- [32] E. DePoy, E. L.N. Gitlin. "Introduction to Research: Multiple Strategies for Health and Human Services. St. Louis: Mosby-Year Book." 1993.
- [33] J. Mason. "Linking Qualitative and Quantitative Data Analysis." *Analyzing qualitative data* 1994: 89-110.
- [34] K. Steinar. "Interviews: An Introduction to Qualitative Research Interviewing." *Studentlitteratur, Lund* 8. 1996.
- [35] B. DiCicco-Bloom, B.F. Crabtree. "The Qualitative Research Interview." *Medical education*. 2006. 40.4: 314-21.
- [36] P. Burnard et al. "Analysing and Presenting Qualitative Data." *British dental journal*. 2008. 204.8: 429-32.
- [37] N. King, C. Horrocks. *Interviews in Qualitative Research*. Sage Publications Limited, 2010.
- [38] N. K. Denzin, Y. S. Lincoln. *The SAGE Handbook of Qualitative Research*. Sage Publications, Incorporated, 2011.
- [39] N. Mays, C. Pope. "Rigour and Qualitative Research." *BMJ: British Medical Journal* 1995. 311.6997:109.
- [40] M. J. Greene. "On the Inside Looking in: Methodological Insights and Challenges in Conducting Qualitative Insider Research." *The Qualitative Report* 2014; 19.29: 1-13.
- [41] B. G. Glaser, A.L. Strauss. "The Discovery of Grounded Theory: Strategies for Qualitative Research." 1967
- [42] C. Teddlie, A. Tashakkori. *Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Approaches in the Social and Behavioral Sciences*. Sage Publications Inc, 2009.
- [43] A. J. Onwuegbuzie, J.P. Combs. "Data analysis in mixed research: A primer." *International Journal of Education* 2011; 3.1: 13.
- [44] A. J. Onwuegbuzie, C. Teddlie. "A Framework for Analyzing Data in Mixed Methods Research." *Handbook of mixed methods in social and behavioral research* 2003: 351-83.
- [45] D. Hellawell. "Inside-out: Analysis of the insider-outsider Concept as a Heuristic Device to Develop Reflexivity in Students Doing Qualitative Research." *Teaching in higher education* 2006; 11.4: 483-94.
- [46] N. Naples. "The insider/outsider debate: A feminist revisiting." *Feminism and method: Ethnography, discourse analysis, and activist research* 2003: 49-66.
- [47] A. Loxley, A. Seery. "Some philosophical and other related issues of insider research." *Skies P., and Pottis A. Researching education from the inside, UK, Routledge* 2008: 15-32.
- [48] J. L. Aguilar. "Insider Research: An Ethnography of a Debate." *Anthropologists at home in North America: Methods and issues in the study of one's own society* 1981: 15-26.
- [49] D. DeLyser. "'Do You Really Live here?'" Thoughts on Insider Research*." *Geographical Review* 2001; 91.1-2: 441-53.
- [50] J. Hewitt-Taylor. "Insider Knowledge: Issues in Insider Research." *Nursing Standard* 2002; 16.46: 33-5.
- [51] B. Workman. 'Casing the joint' Explorations by the insider-researcher preparing for work-based projects. *Journal of Workplace Learning*, 2007; 19(3), 146-160.
- [52] S. B. Merriam et al. "Power and Positionality: Negotiating insider/outsider Status within and Across Cultures." *International Journal of Lifelong Education* 2001; 20.5: 405-16.
- [53] L. Murray, B. Lawrence. "The Basis of Critique of Practitioner-Based Enquiry." *Insider-Research, London: Sage* 2000
- [54] Y. S. Lincoln, E.G. Guba. *Naturalistic Inquiry*. 75 Vol. Sage, 1985.
- [55] E. G. Guba. "Criteria for Assessing the Trustworthiness of Naturalistic Inquiries." *ECTJ* 1981; 29.2: 75-91.
- [56] R. S. Kaplan, D. P. Norton. "Using the balanced scorecard as a strategic management system." 1996.
- [57] E. C. Nelson, P. B. Batalden, M. M. Godfrey. *Quality by Design: A Clinical Microsystems Approach*. Jossey-Bass, 2007.
- [58] Parliamentary and Health Service Ombudsman. "Six Lives: The Provision of Public Services to People with Learning Disabilities." 2009
- [59] G. R. Johnson, R. Whittington, K. Scholes. "Exploring Strategy, Ed." 2011
- [60] E. Emerson et al. "Trends in Age-Standardised Mortality Rates and Life Expectancy of People with Learning Disabilities in Sheffield Over a 33-Year Period." *Tizard Learning Disability Rev* 2014; 19.2: 90-5.
- [61] P. Heslop et al. "The Confidential Inquiry into Premature Deaths of People with Intellectual Disabilities in the UK: A Population-Based Study." *The Lancet* 2014; 383.9920: 889-95.
- [62] G. Glover, E. Emerson. "Estimating how Many Deaths of People with Learning Disabilities in England could be Prevented by Better Medical Care." *Tizard Learning Disability Rev* 2013; 18.3: 146-9.
- [63] S. R. Leeder, A. Dominello. "Health, Equity and Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities* 2005; 18.2: 97-100.
- [64] S. Carlisle. "Health Promotion, Advocacy and Health Inequalities: A Conceptual Framework." *Health promotion international* 2000; 15.4: 369-76.
- [65] N. Lennox et al. "Are a Health Advocacy Diary and Health Assessment Welcomed by those Who use them?". *Journal of Intellectual Disability Research*. Blackwell Scientific 2004; 354-354.
- [66] K. Fisher. "Health Disparities and Mental Retardation." *Journal of Nursing Scholarship* 2004; 36.1: 48-53.
- [67] D. Cooksey. *A review of UK health research funding*. The Stationery Office, 2006.
- [68] M. Polanyi. "Personal Knowledge: Towards a Post-Critical Philosophy." 1962.
- [69] I. Nonaka. "A Dynamic Theory of Organizational Knowledge Creation." *Organization science* 1994; 5.1: 14-37.
- [70] D. Stewart, M. Todd. "Role and Contribution of Nurses for Learning Disabilities: A Local Study in a County of the Oxford-Anglia Region." *British Journal of Learning Disabilities* 2001; 29.4: 145-50.
- [71] J. Foster. "Learning Disability Liaison Nurses in Acute Hospitals: Is there Evidence to Support the Development of this Role? Julie Foster Examines the Current Literature to Discover the Effectiveness of the Liaison Nurse Role and to Look for Evidence to Inform the Development of Learning Disability Liaison Nurse Roles in Acute Healthcare Settings." *Learning Disability Practice* 8.4 (2005): 33-8.
- [72] M. Brown et al. "Learning Disability Liaison Nursing Services in south-east Scotland: A mixed-methods Impact and Outcome Study." *Journal of Intellectual Disability Research* 2012; 56.12: 1161-74.
- [73] Mencap. "Public loses faith in NHS for failing people with a learning disability." Mencap 2014
- [74] E. Emerson et al. "Improving health and lives: the learning disabilities public health observatory." *Advances in Mental Health and Intellectual Disabilities* 2012; 6.1: 26-32.
- [75] Mencap. NHS Primary and Secondary Health Care Charter. Mencap 2013
- [76] G. Iacobucci. "Troubled mental health trust is still putting patients at risk, warns CQC." *BMJ: British Medical Journal (Online)* 2016; 353
- [77] C. Chavez. Conceptualizing from the inside: Advantages, complications, and demands on insider positionality. *The qualitative report*, 2008; 13 (3): 474-494.
- [78] W. Pillow. Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International Journal of Qualitative Studies in Education*, 2003; 16 (2), 175 – 196.
- [79] Sheffield Teaching Hospitals Foundation Trust Learning Disability Annual Report 2015-16
- [80] Sheffield Teaching Hospitals Foundation Trust Carers Strategy 2016 (in development)
- [81] Leeds Teaching Hospitals Learning Disability Patient Survey (2013)
- [82] National Adult Learning Disability Inpatient Survey 2015
- [83] Six Lives – Department of Health second progress report (2013)
- [84] Transforming Care for People with Learning Disabilities – next steps. HMSO 2015