

By Rocco Friebe and Laia Maynou

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Assessing The Dangers Of A Hospital Stay For Patients With Developmental Disability In England, 2017–19

Rocco Friebe (r.friebe@lse.ac.uk), London School of Economics and Political Science and Center for Global Development Europe, London, United Kingdom.

Laia Maynou, Universitat de Barcelona, Barcelona, Spain; London School of Economics and Political Science; and CRES-Universitat Pompeu Fabra, Barcelona.

ABSTRACT People with developmental disability have higher health care needs and lower life expectancy compared with the general population. Poor quality of care resulting from interpersonal and systemic discrimination may further entrench existing inequalities. We examined the prevalence of five avoidable in-hospital patient safety incidents (adverse drug reactions, hospital-acquired infections, pressure ulcers, postoperative pulmonary embolism or deep vein thrombosis, and postoperative sepsis) for four developmental disability groups (people with intellectual disability, chromosomal abnormalities, pervasive developmental disorders, and congenital malformation syndrome) in the English National Health Service during the period April 2017–March 2019. We found that the likelihood of experiencing harm in disability groups was up to 2.7-fold higher than in patients without developmental disability. Patient safety incidents led to an excess length-of-stay in hospital of 3.6–15.4 days and an increased mortality risk of 1.4–15.0 percent. We show persisting quality differences in patients with developmental disability, requiring an explicit national policy focus on the needs of such patients to reduce inequalities, reach parity of care, and lower the burden on health system resources.

In high-income countries, up to 3 percent of the population was living with a developmental disability as of 2016.¹ These include intellectual disability, pervasive developmental disorder, congenital malformation syndrome, or chromosomal abnormality. Such disabilities may be caused by factors such as genetics, prenatal exposure to hazards, birth injuries, childhood brain infection, and iodine deficiency.² Previous research has found great discrepancies in life expectancy and health care needs between people with developmental disability and those in the general population,^{3,4} with evidence highlighting the potential to reduce these gaps through improved access to high-quality and safe medical care, services, and supports.⁵

Even though high-quality health care is a fundamental aim of health care systems,⁶ with patient safety improvement strategies such as teamwork training or infection control implemented to improve the safety of hospitals,⁷ patients still face significant risks of experiencing harms when treated in hospital settings.⁸ Estimates suggest that about one in twenty patients suffer from preventable physical injury when hospitalized,⁹ with adverse events ranked as the fourteenth leading cause of morbidity and mortality globally as of 2013.¹⁰ In a report published by the Department of Health and Human Services Office of Inspector General in May 2022, 25 percent of Medicare patients discharged from hospitals experienced harm during their hospital stays, including medication

errors, pressure injuries, or hospital-acquired infections.¹¹ Almost half of all events were caused by substandard or inadequate care and therefore were deemed preventable.

The burden of patient safety incidents is also substantial in other health care systems. For example, in the taxpayer-funded English National Health Service, a study published in 2017 found that healthy life years lost by six common patient safety incidents were comparable to those lost because of multiple sclerosis, HIV/AIDS, tuberculosis, or cervical cancer in England.¹² The Organization for Economic Cooperation and Development estimated in 2017 that up to 15 percent of all hospital activity and expenditure was in direct response to such patient safety failures.¹³ These realities have placed patient safety at the forefront of the policy agenda.¹⁴

Patient safety incidents disproportionately affect disadvantaged and high-need population groups,¹⁵ including elderly patients or those living with advancing illnesses, further entrenching inequalities. Factors associated with rising risks in this patient group relate to the frequency of hospitalization, the complexity of care needs, the reliance on caregivers to provide advocacy and care tasks during the hospital stay, and negative attitudes by hospital staff.¹⁶

Even though adult patients with developmental disability are considered a high-need patient group, few studies have investigated patient safety incidents specifically in this population.^{17–20} Existing research reported that patients with developmental disability received lower-quality hospital care processes²¹—for example, during chemotherapy and certain surgical interventions—and experienced worse outcomes, including iatrogenic harm in 36.7 percent of pediatric patients with intellectual disabilities and high levels of preventable hospital readmission rates.²² Similarly, a chart review in the United States published in 2002 found that approximately one in three patients with a developmental disability received medication (often psychotropic drugs) that was not based on any prior diagnosis.²³ Despite the salience of this issue to patients, policy makers, caregivers, and advocates, there have been few attempts to systematically assess the experiences and outcomes of people with developmental disability.²¹

One example of such an attempt is the 2021 Learning from Lives and Deaths (LeDeR) program in England²⁴ (formerly the Learning from Deaths Review Programme, established in 2015), which was set up to assess the circumstances surrounding the death of people with “learning disabilities” (intellectual disability) and to derive lessons for future quality improvement.²⁵ This program evolved in response to

awareness about the avoidable in-hospital deaths of six patients with developmental disability that were linked to poor clinical care.²⁶ Reviews conducted as part of LeDeR reported that as of 2018, approximately 13 percent of all deaths were caused by poor quality of hospital care, including negligence and abuse,²⁷ ultimately guiding the UK government objective to shift care for patients with learning disability and autism from the in-hospital setting into the community.²⁸ However, more than half of these reviews have been a result of notification by family members, instead of being flagged by health care providers or allied health professionals.²⁴ A data-driven approach to systematically monitoring outcomes for patients with developmental disability could therefore enhance the identification of hospital failures, although the efficacy of routinely collected patient-level hospital data for such purposes in patients with developmental disability remains unknown.

In this study we investigated the prevalence of five common and preventable in-hospital patient safety incidents (adverse drug reactions, hospital-acquired infections, pressure ulcers, postoperative pulmonary embolism or deep vein thrombosis, and postoperative sepsis) in adult inpatients with developmental disability and the causal impact they have on patient outcomes (in-hospital mortality and length of stay) in the English National Health Service (NHS). Our findings can inform the development of effective policies and quality improvement strategies to reach parity of care for people with developmental disability.

Study Data And Methods

SAMPLE We used administrative, individual-level data for all NHS hospital inpatients admitted and discharged between April 2017 and March 2019 from the Hospital Episode Statistics database, which was obtained through NHS Digital (the nondepartmental public body responsible for information, data, and information technology systems in the English NHS). Data entailed information from deidentified patient records, including patient demographic characteristics, diagnoses, procedures performed, and patient outcomes such as in-hospital death. Hospital Episode Statistics data are recorded in finished episodes of care that relate to the clinician responsible for a respective aspect of the care pathway. We combined all episodes from day of admission to day of discharge or in-hospital death, allowing an assessment of the risk for adverse events during the entirety of a hospital stay.

Our study sample included any adult patient age eighteen or older and excluded patients seen

as day-case admissions (commonly an elective admission without intent for overnight stay) who were identified through validated diagnostic codes. We obtained patient characteristics, including age, sex, comorbidities, treatment intensity, and type of admission (emergency admission, commonly via emergency departments, or planned admission). To account for complexity, for each patient we calculated the Charlson Comorbidity Index based on the number of comorbidities recorded in the patient file on admission.²⁹

We identified patients with a developmental disability based on validated diagnostic codes recorded in patient records according to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10)³⁰ (see online appendix exhibit 1).³¹ We categorized patients into four developmental disability groups: intellectual disability (mild, moderate, severe, and profound), pervasive developmental disorder (autism, overactive disorders, and Asperger syndrome), congenital malformation syndrome (tuberous sclerosis, fetal alcohol syndrome, fetal hydantoin syndrome, Aarskog syndrome, Prader-Willi syndrome, Cornelia de Lange syndrome, Seckel syndrome, Rubinstein-Taybi syndrome, and Santos syndrome), and chromosomal abnormalities (Down syndrome, female with more than three chromosomes, and fragile X syndrome). To account for the possibility that a patient's developmental disability was not recorded during the study period, we imputed any such diagnosis that was made at any prior hospital admission leading back to April 2000.

PATIENT SAFETY EVENTS AND OUTCOMES Our analysis focused on five common and avoidable patient safety incidents: adverse drug reactions, hospital-acquired infections, pressure ulcers, postoperative pulmonary embolism or deep vein thrombosis, and postoperative sepsis. Identification of patient safety indicators was based on ICD-10 codes, and we used Hospital Episode Statistics-specific, translated, and validated inclusion and exclusion criteria originally developed by the Agency for Healthcare Research and Quality^{12,32,33} (see appendix exhibit 2).³¹ The selection of patient safety incidents was based on previous research, including an evaluation of the prevalence of such incidents across different high-need patient groups in the English NHS and the German health care system.¹⁵

To assess the impact of patient safety incidents on outcomes, we calculated patient length-of-stay as the difference between day of admission and day of discharge (or death), and we calculated in-hospital mortality through the recorded discharge method. Patients admitted and dis-

We have demonstrated the need for effective strategies to improve the quality of hospital care for patients with developmental disability.

charged on the same day or without overnight stay were recorded with a zero length-of-stay—for example, when a patient died on the day of admission.

STATISTICAL ANALYSIS Descriptive statistics were used to report the proportion of patient safety incidents across the study period separately by disability group to explore possible heterogeneity linked to varying degrees of health care needs and care complexity.

To assess the probability of a patient safety incident occurring for patients with developmental disability in English NHS hospitals compared to patients without a diagnosed developmental disability, and accounting for case-mix, we employed multivariate patient-level, logistic regression models (see appendix exhibit 3 for model specification).³¹

We then estimated the causal impact of patient safety incidents on in-hospital mortality and length-of-stay based on a counterfactual identified through propensity score matching.³⁴ The propensity score represents the conditional probability of having one of the studied patient safety incidents in patients with developmental disability (1: yes, 0: no), based on a set of patient characteristics (age, sex, Charlson Comorbidity Index, and type of admission), calculated through probit regression analysis. We further included each patient's diagnosis-related group (Healthcare Resource Groups) classification as a predictor variable of the propensity score, allowing us to capture additional, more granular information on disease classification and patient severity. Nearest neighbor matching methods were used to compare treatment and control groups (those with and without a patient safety event), with average treatment effects on the treated allowing for a causal interpretation of outcomes

Including caregivers more frequently and systematically may be an important solution to protect patients.

resulting from exposure to patient safety incidents, assuming balancing criteria were met.

All analyses were performed using Stata SE, version 16.

LIMITATIONS This analysis had several limitations. First, identification of patient safety incidents relied on information recorded in patient-level, administrative data sources. Studies have shown variation in recording practices of adverse events across providers, relating to local culture and clinical awareness.^{35–37} Even though our study used previously validated ICD-10 codes, which had been applied to Hospital Episode Statistics data, it is possible that any findings presented in this research provide an underestimate of the true burden of patient safety incidents both for the general patient population and for patients with developmental disability. However, to facilitate and systematically track the impact of patient safety incidents on outcomes for people with developmental disability, our study provides important insights on the approximate scale of the problem and highlights the feasibility of using administrative data as a tool to systematically identify hospital failures resulting in harm for patients with developmental disability.

Second, the classification of people with developmental disability relied on ICD-10 entries in one of twenty diagnosis fields. It is possible that some developmental disability failed to be recorded when considered to be not clinically relevant. Moreover, in some instances, certain developmental disabilities (for example, mild intellectual disability) might not have been sufficiently pronounced to be identified by the clinical team, leading to underreporting in our study. To address this concern, we imputed any potential in-hospital records of developmental disabilities made outside of our study period (leading back to April 2000). We applied ICD-10 codes that were validated in previous studies, focusing on the identification of patients with developmental disability from administrative data. There remains the residual exclusion of

relevant patients because of a lack of information on diagnoses made outside the hospital environment and when they were younger than age eighteen.

Finally, our assessment of the causal impact of patient safety incidents on outcomes relied on the study of in-hospital mortality and length-of-stay. Although in-hospital mortality is considered a key quality indicator and long length-of-stay is considered undesirable for patients, costly to the health care system, and associated with potential exposure to adverse events, because of data limitations we were not able to assess the long-term implications of patient safety incidents, including on people's mental health, the ability to perform daily tasks, and health services use outside the hospital setting.

Study Results

We identified 15,155,529 hospitalizations in the English NHS between April 2017 and March 2019. A small proportion were related to admissions for people with developmental disability, including intellectual disability (110,749, or 0.73 percent), pervasive developmental disorder (73,961, or 0.49 percent), congenital malformation syndrome (14,442, or 0.10 percent), and chromosomal abnormalities (21,332, or 0.14 percent). Exhibit 1 presents patient characteristics both for patients without developmental disability and by developmental disability group. Notably, patients without diagnosed developmental disability were significantly older and more often female compared with patients in any of the studied developmental disability groups.

Patient safety incidents were recorded in 5.11 percent of all hospitalizations, with hospital-acquired infections being the most common form of adverse event (2.45 percent), followed by adverse drug reactions (1.50 percent) and pressure ulcers (1.20 percent). Only a small proportion of patients suffered from postoperative sepsis (0.68 percent) and postoperative pulmonary embolism or deep vein thrombosis (0.36 percent).

We observed significant variation by type of patient safety incident and developmental disability group (exhibit 2). Based on our multivariate logistic regression analyses (exhibit 3), people with chromosomal abnormalities appeared most likely to experience a patient safety event while hospitalized, with the odds ratios for pressure ulcers (OR: 3.76), hospital-acquired infection (OR: 2.13), postoperative sepsis (OR: 1.85), and postoperative pulmonary embolism or deep vein thrombosis (OR: 1.44) significantly higher compared to patients without a diagnosed developmental disability (with an odds ratio of 1.0).

EXHIBIT 1

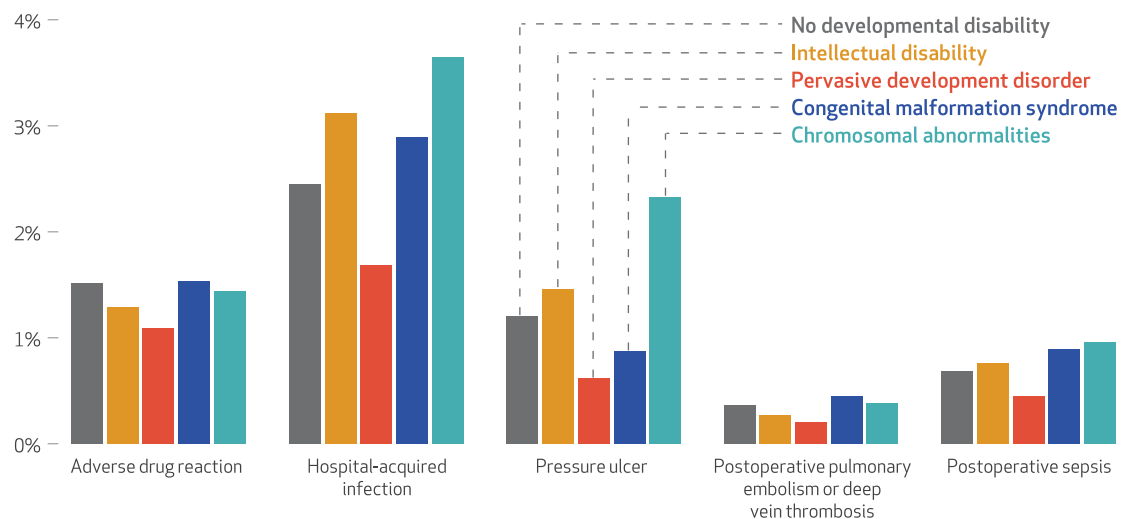
Summary statistics of characteristics and outcome measures for patients admitted and discharged in the English National Health Service between April 2017 and March 2019, by disability category

Patient characteristics	No developmental disability (n = 14,935,045)	Intellectual disability (n = 110,749)	Pervasive development disorder (n = 73,961)	Congenital malformation syndrome (n = 14,442)	Chromosomal abnormalities (n = 21,332)
Sex (%)					
Female	59.42	48.62	43.52	57.84	47.83
Male	40.58	51.38	56.48	42.16	52.17
Age, years (mean)	57.02	46.53	35.11	41.20	46.14
Charlson Comorbidity Index (%)					
0	49.87	53.03	67.20	48.06	49.38
1	20.47	23.51	20.80	19.20	27.93
2	12.40	12.26	6.59	19.12	12.71
3	6.74	5.53	2.56	7.25	5.04
4	3.77	2.67	1.04	3.28	2.18
5	1.86	1.20	0.49	1.10	0.71
6+	4.88	1.81	1.31	1.99	2.05
Emergency (unplanned) admissions (%)	69.32	78.45	77.24	70.03	74.85
No. of procedures (mean)	1.72	1.02	1.10	1.69	1.18
Outcomes (%)					
Adverse drug reaction	1.51	1.29	1.09	1.53	1.44
Hospital-acquired infection	2.45	3.12	1.68	2.89	3.65
Pressure ulcer	1.20	1.46	0.62	0.87	2.33
Postoperative embolism or deep vein thrombosis	0.36	0.27	0.20	0.45	0.38
Postoperative sepsis	0.68	0.76	0.45	0.89	0.96
Length-of-stay, days (mean)	4.42	5.75	4.78	4.55	5.18
In-hospital mortality (%)	2.70	1.97	0.86	1.41	3.32

SOURCE Patient-level administrative data from the Hospital Episode Statistics database, English National Health Service. **NOTES** The specific conditions in each developmental disability group are described in the text. Higher Charlson Comorbidity Index scores indicate greater numbers of comorbid conditions.

EXHIBIT 2

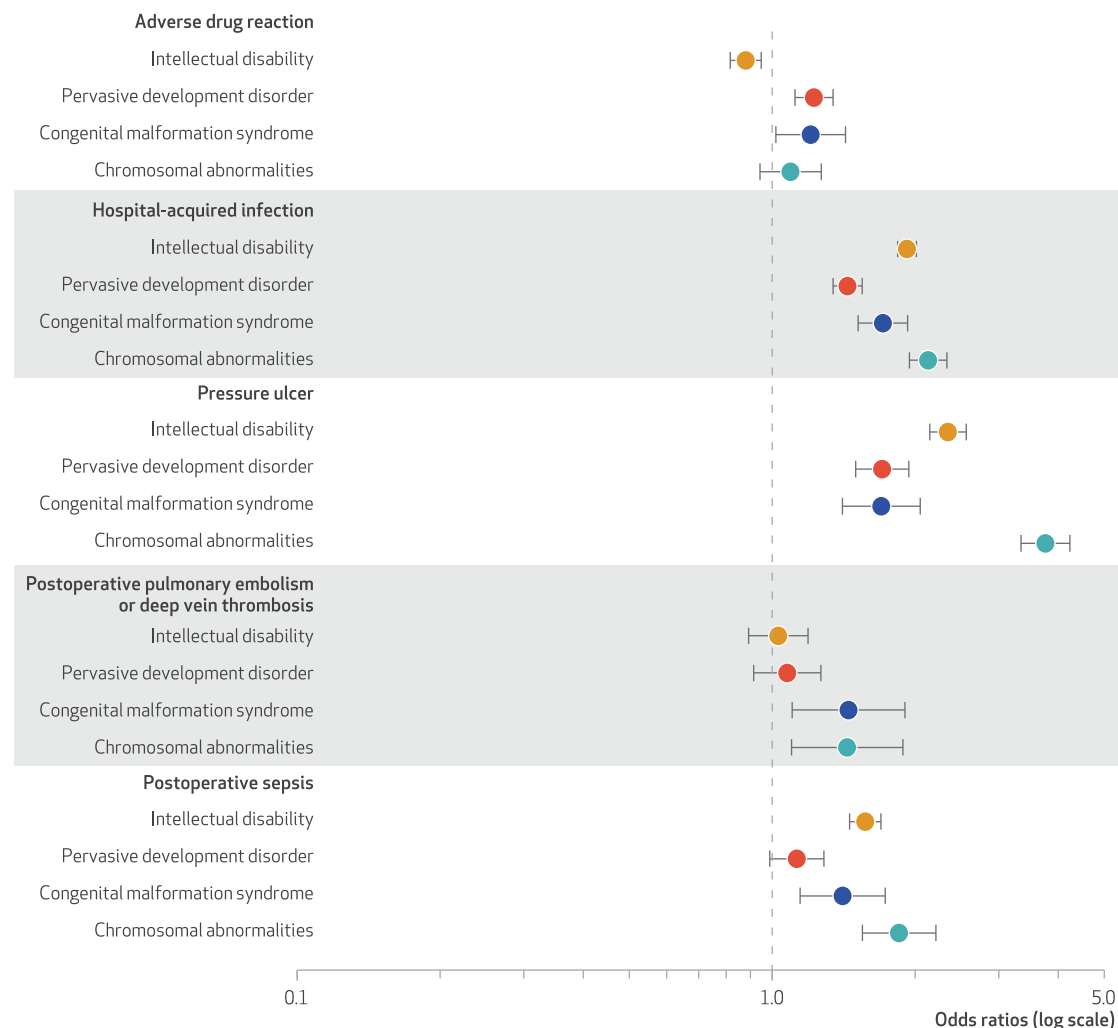
Prevalence of 5 avoidable in-hospital patient safety incidents reported separately for patients with no developmental disability and patients in 4 developmental disability groups, among patients admitted and discharged in the English National Health Service between April 2017 and March 2019



SOURCE Percentages calculated based on information from the Hospital Episode Statistics database, English National Health Service. **NOTE** The specific conditions in each developmental disability group are described in the text.

EXHIBIT 3

Likelihood of experiencing 5 avoidable in-hospital patient safety incidents for people belonging to 4 developmental disability groups for patients admitted and discharged in the English National Health Service between April 2017 and March 2019



SOURCE Logistic regression analysis based on information from the Hospital Episode Statistics database, English National Health Service. **NOTES** Logistic models specified. Dependent variables are the 5 patient safety incidents. Models controlled by age, age squared, sex, Charlson Comorbidity Index, developmental disability group, type of admission (emergency admission), number of procedures, weekdays, month, year, and hospital fixed effects. Standard errors are clustered at the hospital level. The specific conditions in each developmental disability group are described in the text. The odds ratio 1.0 represents patients with no diagnosed developmental disability.

Similarly, patients with intellectual disability had higher odds for experiencing pressure ulcers (OR: 2.34), hospital-acquired infection (OR: 1.92), and postoperative sepsis (OR: 1.57). Although both of those patient groups had no statistically higher odds for an adverse drug reaction, the likelihood of such event occurring in patients with pervasive developmental disorder (OR: 1.22) and congenital malformation syndrome (OR: 1.21) was significantly higher. Moreover, patients with pervasive developmental disorder also experienced higher odds for pressure ulcers (OR: 1.70) and hospital-acquired infec-

tions (OR: 1.44), whereas patients with congenital malformation syndrome experienced higher odds for hospital-acquired infections (OR: 1.71), pressure ulcers (OR: 1.70), postoperative pulmonary embolism or deep vein thrombosis (OR = 1.45), and postoperative sepsis (OR: 1.41).

On the basis of these findings, the likelihood of patients with developmental disability experiencing any one of the five patient safety incidents was raised by between 20 percent and 276 percent (2.7-fold) compared to patients without a developmental disability and accounting for key demographic and clinical character-

istics (data not shown).

We estimated the causal impact of patient safety incidents in patients with developmental disability compared to a counterfactual without patient safety incidents and without diagnosed developmental disability determined through propensity score matching on length-of-stay and in-hospital mortality (see exhibit 4 and appendix exhibit 4).³¹ Across all patient safety incidents and disability groups, length-of-stay increased between 3.6 and 15.4 additional days. Postoperative sepsis caused the longest increase (approximately fourteen additional days), whereas adverse drug reactions caused the shortest increase (approximately four additional days), in excess length-of-stay. Mortality risk after a patient safety incident rose between 1.4 per-

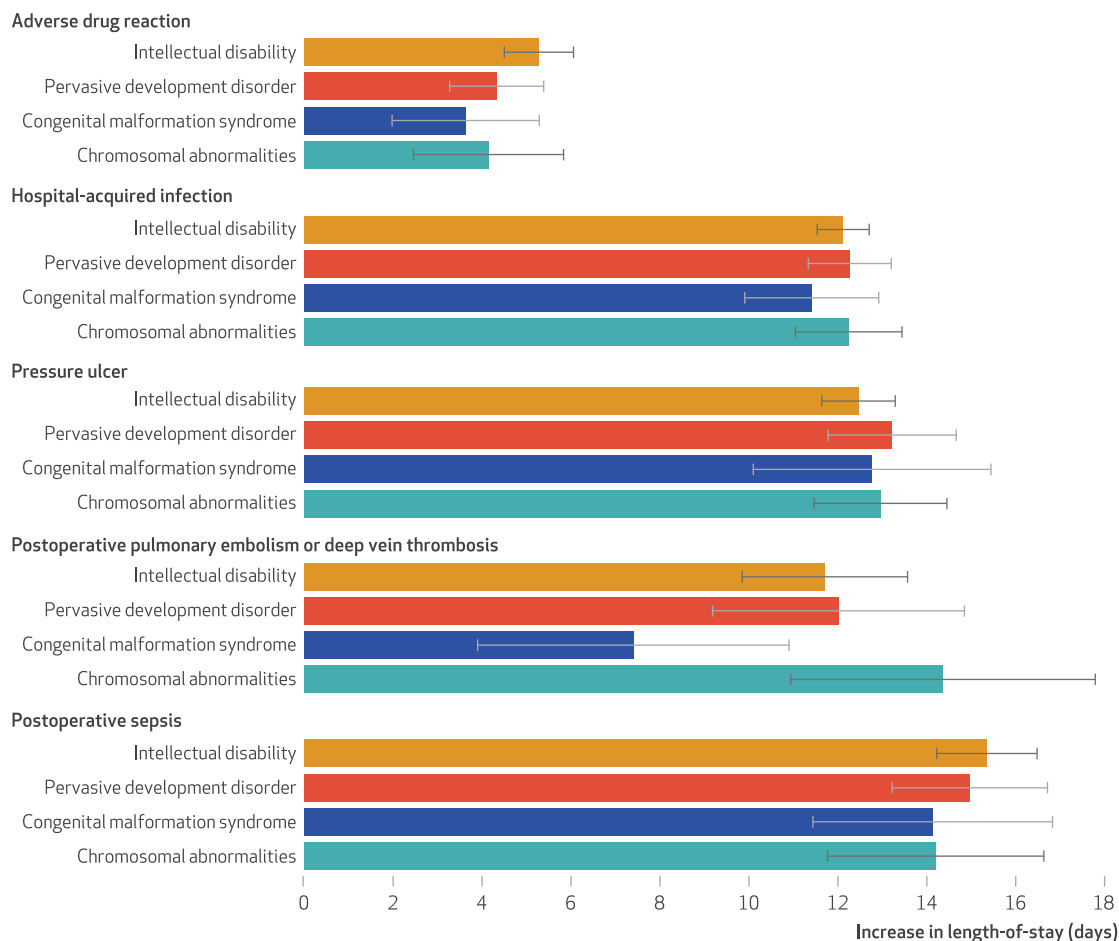
cent and 15.0 percent. The largest increases were seen for patients with chromosomal abnormalities and postoperative sepsis (14.7 percent) and hospital-acquired infections (14.5 percent) (see the appendix).³¹

Discussion

Using administrative hospital data from the English NHS during the period April 2017–March 2019, we found that patients with developmental disability were disproportionately affected by patient safety incidents (up to 2.7-fold more likely to experience harm compared to patients without a diagnosed developmental disability) during the study period. High rates of hospital-acquired infections and pressure ulcers

EXHIBIT 4

Causal implications of an avoidable patient safety incident on excess length-of-stay in hospital for people in 4 developmental disability groups among patients admitted and discharged in the English National Health Service between April 2017 and March 2019



SOURCE Causal inference estimation based on information from the Hospital Episode Statistics database, English National Health Service. **NOTES** Average treatment effect on the treated is reported. Propensity score matching were based on age, sex, Charlson Comorbidity Index, emergency admissions, and Healthcare Resource Groups code. The balance test was fulfilled for all models. The specific conditions in each developmental disability group are described in the text.

were recorded for people with chromosomal abnormalities, although most of the assessed patient groups also experienced above-average rates of postoperative pulmonary embolism or deep vein thrombosis and postoperative sepsis. Our study provides evidence on the causal impact of such patient safety incidents on outcomes, showing significant increases in mortality risk and length-of-stay. Our findings are important because we have demonstrated the need for effective strategies to improve the quality of hospital care for patients with developmental disability, and we highlight the suitability of administrative data to systematically identify relevant patient safety incidents for disadvantaged patient groups.

In addition to our main findings, we also report significant differences in the age and sex profile of patients with developmental disability compared to patients without any recorded developmental disability. On average, in-hospital patients with developmental disability were ten to twenty years younger than the general hospital population. Except for patients with congenital malformation syndrome, a greater proportion of patients with developmental disability were males. These findings suggest ongoing challenges in the provision of adequate services within the community that address the needs of people with developmental disability to enable a healthy life.

For patients without any developmental disability, the rate of selected patient safety incidents identified in our study aligned with previous findings from England, being higher than those reported for other health care systems in Europe (for example, Germany)¹⁵ and lower than in the US as of 2010.³⁸ Despite cross-national variation that may suggest quality differences in hospital care, it is possible that data on patient safety incidents are confounded by organizational and professional factors, including varying recording practices.

Our results add to previous work, which has suggested that high-need patient groups are more likely to experience patient safety incidents and, specifically, that patients with developmental disability have poorer hospital experiences.¹⁶ To our knowledge, this is the first study to assess the level of patient safety incidents experienced by patients with developmental disability at a system level.

Policy Implications

Although our findings highlight an increased risk of experiencing patient safety incidents if part of any of the selected developmental disability groups, we were unable to determine the un-

derlying factors causing harm. However, more policy emphasis must be given to the management of patients with complex needs to address interpersonal shortcomings related to staff communication practices, possibly linked to lack of awareness and education, the poor pursuit of basic care standards, and delays in diagnostics and treatment. Including caregivers more frequently and systematically, with sufficient funding for them to perform that role as a part of the hospital care team, may be an important solution to protect patients against patient safety incidents, as familiar caregivers are quicker to notice when someone is not at their baseline and know their routine care needs and accommodations.

Our findings support the current UK government objective to shift care for patients with learning disability and autism from the hospital into the community in England,²⁸ which may reduce the number of patients exposed to patient safety failures. However, this will require significant strengthening of existing community services through appropriate resourcing and a widened focus on patients with developmental disability to reduce existing inequalities.

We highlight the need to consider the cost implications resulting from avoidable patient harm—for example, those caused by an extended length-of-stay—and the associated care needs. This also includes the use of interventions to improve the health of populations, including using health checks,³⁹ to proactively recognize problems before they advance to the point of needing hospitalization. For inpatients, hospitals should adopt approaches to identifying those at risk, possibly on admission, and systematically monitor their experiences across the patient pathway to avoid outcomes similar to those described in the English NHS. Hospital staff should also be required to participate in training on developmental disability, raising awareness about specific care needs and priming staff for interactions with high-need patient groups to reduce stigma and biases.

Conclusion

An improved understanding of the scale of avoidable patient safety incidents in patients with developmental disability is a crucial first step toward developing and implementing targeted and effective quality improvement strategies.⁴⁰ This article has reported on the substantial disparities in patient safety incidents that exist across four distinct patient groups with developmental disability in England for the period April 2017–March 2019. Patient safety incidents in these patient groups cause a significant increase in in-hospital mortality and extended hospital

stays. It is vital that health systems adopt a proactive approach to identifying patients at risk and systematically monitor patients' experiences. Expanding national policy to explicitly focus

on the need of high-need patient groups will be necessary to reduce existing inequalities, reach parity of care, and lower the burden on health system resources. ■

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data analyzed is NHS Digital. Patient-level data are available subject to their information governance requirements. The authors will share aggregate data and coding scripts on request. This is an open access article distributed in accordance with the terms of the

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