

Plenary

P1 IMPACT OF AUSTERITY ON FAMILIES WITH DISABLED CHILDREN IN EUROPE

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Aims To determine impact of austerity on families with disabled children across Europe.

Methods Cross-sectional electronic surveys in 25 languages disseminated via professional and family networks in 32 European countries December 2016 – February 2017.

Country comparison groups: United Kingdom (UK); countries where >50% professionals and families reported austerity cuts; remaining countries.

United Nations International Children's Emergency Fund (UNICEF) indicators of severe poverty in rich and middle-income countries were integrated into the families' questionnaire: those reporting ≥four poverty indicators met severe poverty criteria.

Level of dependency of disabled child accounted for in analysis, using IBM SPSS Statistics, v23.

Results Responses received: 959 professionals (32 countries); 731 families (23 countries).

Family respondents: 29% (215/731) UK; 28% (275/731) other countries reporting austerity cuts; 33% (241/731) remaining countries.

45% (332/731) met UNICEF severe poverty criteria.

More UK families reported worsening quality of services compared to three years ago (112/215; 52.1%), than families not in poverty with completely dependent disabled children from remaining countries (14/69; 20%) ($p < 0.001$, $\chi^2 = 57.1$).

More UK families in poverty with completely dependent disabled children reported access more difficult than three years ago than any other respondent groups to: therapies (85%, 33/39); support in education (67%, 26/39); social care support (85%, 33/39); welfare support and benefits (79%, 31/39). Significantly fewer respondents from remaining countries reported more difficult access to services ($p < 0.001$ for all).

Families and professionals from remaining countries generally perceived health, education and social care needs were better addressed than 10 years ago, whilst most of all other comparison groups reported needs in all areas to be less well met ($p < 0.001$). UK families in severe poverty with completely dependent disabled children reported the greatest decline in how health, education and social care needs were met, compared to 10 years ago.

Conclusion Professional and family respondents across Europe experiencing austerity cuts reported a significant decline in quality of services received in the last three years and in how well health, educational and social care needs had been met over the last decade, compared to respondents from countries experiencing no austerity measures.

UK responses were significantly worse than from other countries. UK families with the most dependent disabled children living in poverty generally reported the worst experiences overall.

P2 PATTERN OF DELAYS IN SEEKING LEGAL JUDGEMENTS TO WITHDRAW LIFE-SUSTAINING THERAPY

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Aims In recent years legal judgements have being sought more frequently to allow withdrawal of life-sustaining therapy (LST) for patients in paediatric intensive care units (PICUs). Anecdotally, units can experience very long delays during the legal process. In order to clarify the current situation we have surveyed the medico-legal experience of UK PICUs over the last 5 years.

Methods A questionnaire was distributed to PICU Consultants with an interest in the medico-legal process in each UK PICU to collect relevant data.

Results Data was returned from 26 centres and a total of 15 cases were identified. 73% of children were under 1 year of age, 87% of children were under the age of 2 years. The interval between notifying the Trust medico-legal department and a first court date varied from 2 days to 16 weeks and the overall delay between notifying the Trust medico-legal department and obtaining a final judgement varied with a biphasic distribution; 31% of cases were dealt with as emergencies and concluded in less than 2 weeks, 61% of cases, considered more 'stable' took up to 6 months to resolve. 8% of cases took longer than 6 months to resolve, with the longest taking 14 months.

Conclusion Our findings demonstrate that whilst a minority of cases are dealt with promptly; around two-thirds of cases include considerable time delays. Prolonged admissions in this context result in extended periods of invasive treatment which are not in children's best interests, considerable disruption to families and siblings, and enormous stresses on PICU staff. In addition there is considerable financial cost in terms of resources and legal fees. PICU staff should engage with the Family Division of the High Court to develop a fast-track process for dealing with these cases.

P3 SLEEP FOR YOUR OWN HEALTH: A PAN-UK SURVEY ON PAEDIATRICIANS' EXPERIENCE OF SLEEP AROUND SHIFT WORK

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Aim Healthy sleep practices improve alertness and performance, with positive benefits to personal health and patient safety. Last year we surveyed the London School of Paediatrics (LSP) trainees' regarding their experience of night shifts. These were used to raise the profile of this issue, and to promote mandatory training on healthy sleep. We now sought to assess the impact of this educational drive, and to survey the experiences of all UK paediatricians on this topic.

Methods An online survey was created using Typeform and disseminated to all UK paediatricians via the RCPCH Heads of School, local TPDs and a link on e-portfolio.

Results 768 paediatricians responded, with participants from every UK deanery. Most represented were West Midlands (15%), London (13%) and Scotland (11%). 704 (92%) of respondents were trainees, representing roughly 16% of all