

Austerity and families with disabled children: a European survey



European Academy of
Childhood Disability



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ABBREVIATION

EACD European Academy of
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AIM To describe the impact austerity measures have had on families with disabled children across Europe and on professionals providing services for them.

METHOD Cross-sectional surveys were disseminated via professional and family networks in 32 European countries for 3 months from December 2016.

RESULTS Families ($n=731$), of whom 45% met UNICEF criteria for severe poverty, and professionals ($n=959$) responded from 23 and 32 countries respectively. Respondents were grouped into those from countries with and without austerity. The direct and indirect impact of austerity cuts and worse working conditions were reported more often by professionals from countries with austerity, compared to those without. Most families reported services to be worse in quality than 3 years ago. Families with completely dependent disabled children said the needs of their disabled children are significantly less well met now, compared to 10 years ago.

INTERPRETATION A decline in quality of services for disabled children was reported by most family and many professional respondents across Europe, regardless of austerity. Where implemented, austerity measures were reported to have impacted significantly on families with disabled children.

The political response in many countries across Europe to the banking crisis that started in 2008 has been to impose austerity measures, including cuts to welfare benefits and public services. Austerity measures impact more on the most vulnerable, including families with one or more disabled children,* who are more likely to experience poverty which becomes more entrenched as the effects of 'welfare reforms' accumulate.¹ UNICEF's 2014² and 2016³ reports evidence the strong relationship between the impact of recession on national economies and a decline in children's well-being since 2008, with an unprecedented increase in the numbers of children living in severe material deprivation.

*We use the term 'disabled child/children' deliberately. Generally we prefer 'person-first language' because it is more appropriate to describe people 'with' or who 'have' specified characteristics, such as impairments or specific diagnoses. However, consistent with the International Classification of Functioning, Disability and Health, disability is created as a consequence of interaction between a person and their environment. Disability cannot be considered as intrinsic to the person. Hence, we believe that people are in fact disabled, and not 'people with disabilities'.

The 2014 report of the Organisation for Economic Co-operation and Development highlights that since the economic recession, children and young adults are more at risk of poverty than the elderly for the first time.⁴ UNICEF called on countries to produce better data on the recession's impact on children's well-being, to place the well-being of children at the top of their responses to the recession, and to promote opportunities to break the cycles of child vulnerability.² In addition, Eurostat stated that 88 300 children claimed asylum in Europe in 2015 (about one-fifth of the total number of child refugees), but at least 10 000 unaccompanied children have dropped off Europol's radar, thought to have fallen into the hands of organized trafficking syndicates.⁵

UNICEF's The State of the World's Children report in 2013 was dedicated to disabled children. It made key recommendations and concluded, in line with the United Nations Convention on the Rights of the Child: 'The ultimate proof of all global and national efforts will be local, the test being whether every child with a disability enjoys her or his rights – including access to services, support, and opportunities – on a par with other children,

even in the most remote settings and the most deprived circumstances'.⁶

Many Eastern European countries are striving to deinstitutionalize disabled children, reintegrating them with their own or new families, and are developing services to better support them in their communities.⁷⁻⁹ For most countries, lack of robust population data about the many needs and situations of disabled children and young people prevents these from becoming visible.^{10,11} Surveys in 2015 of the National Coordinators of the European Academy of Childhood Disability (EACD),¹² and of members of the British Academy of Childhood Disability and British Association for Community Child Health¹³ confirmed the adverse impact of austerity cuts directly on families with one or more disabled children as well as on the services they required to meet their many needs.

The aim of this study was to make visible the experience of families with disabled children and young people across Europe. This was achieved by listening to their views, as well as to the views of professionals who provide services for them, to determine the direct experience of families of austerity cuts and the indirect impact on families of cuts to the services they need.

METHOD

Study design

The EACD is an academic association of professionals working with disabled children throughout Europe. A parent carer representative sits on the management committee. The professional body in the field of childhood disability in each country nominates a national coordinator: a health professional who represents professionals working with disabled children in that country, who acts as a link to the EACD. At the time of the study, 28 national coordinators were senior paediatricians or paediatric neurologists, three were senior physiotherapists. A cross-sectional survey design captured the views of national coordinators of the EACD (or other leaders in paediatric disability where no national coordinator was in place), families with disabled children, and professionals who provide services for them across Europe.

Surveys for national coordinators included questions regarding cost and access to health services, education, social care, and welfare support for disabled children and young people (hereafter, 'children' refers to children and young people) to ascertain the socio-political context in each country, the availability and delivery model of services for disabled children and their families, as well as the current and expected numbers of disabled child refugees (Appendix S1, online supporting information). All national coordinators willingly shared this information, knowing that it would be published, as they wanted to highlight the challenges faced in their countries. Surveys for professionals and families were designed by the first author with input from all authors, mindful of the findings of a recent UK survey¹⁴ (Appendices S2 and S3, online supporting information). The World Health

What this paper adds

- Stigma about disability remains a challenge in many countries across Europe.
- Most families and many health care professionals reported worsening quality of services than 3 years ago, regardless of austerity.
- Austerity cuts are reported to have impacted especially negatively on families with dependent disabled children.

Organization UNICEF indicators of severe poverty in high- and middle-income countries were integrated into the families' questionnaire: those reporting four or more poverty indicators met the criteria for severe poverty.² Surveys for professionals and families included questions regarding direct and indirect experiences of austerity cuts, access to services and support, and reflections on how well needs had been met over time (Appendices S2 and S3).

Participants

Participants were national coordinators, families with disabled children, and professionals providing services for disabled children. National coordinators were asked to provide email contacts for leads of professional networks working with disabled children as well as of families' and disabled young people's networks to enable dissemination of links to the surveys. National coordinators were also asked to indicate in which languages these surveys were required.

Survey dissemination and sampling

Preliminary translations of the surveys for professionals and families were from English into 25 languages using Google auto-translate. Translated surveys were then validated by student volunteers from the University of Sunderland and by EACD contacts who were fluent in the appropriate language. The survey questions were uploaded on to online survey software (www.surveygizmo.com) by the second author. Using non-probability convenience sampling, all surveys were shared via member organizations of disabled young people, parent carers, and professionals who agreed to collaborate with the EACD by sharing the survey links with their members. Participation was entirely voluntary and consent implied by participation. The chair of the Sunderland National Research Ethics Committee advised no further ethical permission was required. National coordinators who did not return a completed survey within 1 month were sent a reminder from the chair of EACD (GC).

The professionals' and families' survey links were open for 3 months from December 2016. Each week, charts of response rates from families and professionals by country were sent to national coordinators to stimulate interest and encourage further responses.

Analysis

The European Union's Maastricht criteria outlined that European Union member states may not have a national debt of greater than 60% of their gross domestic products, or have a budget deficit that exceeds 3%

of their gross domestic products.¹⁵ Using this principle, survey responses from families and professionals were grouped into countries in austerity if they had greater than 60% national debt and greater than 3% budget deficit according to their 2015 to 2016 average for national debt and budget deficit.¹⁶ France, Portugal, Spain, and the UK fitted the criteria for austerity; remaining countries with 60% or less national debt and 3% or less budget deficit were grouped into the no austerity group. This resulted in 899 respondents falling into the austerity group and 791 into the no austerity group (Table SI, online supporting information).

Family respondents were further categorized into those in severe poverty (reporting four or more UNICEF poverty indicators) or not in severe poverty (reporting three or fewer UNICEF poverty indicators). Families were also grouped by whether they had completely dependent disabled children or not.

Survey data analysis was performed by the second author. Questionnaire responses were downloaded into Microsoft Excel. Statistical analyses were calculated using SPSS version 24 (IBM Corp., Armonk, NY, USA). Differences between reports of how well needs were met, by health, education, and social services, between 10 years ago and now (questions 16–18 and 18–20 [Appendices S2 and S3]) were calculated. χ^2 analysis was used for categorical responses from the surveys completed by professionals to compare the effect of austerity on responses, and on responses from families comparing the influence of austerity, dependency level of the disabled child, or severe poverty. Independent *t*-tests were used to analyse continuous survey results regarding waiting times and changes in scores regarding how well needs were reported to be met by health, education, and social services. A robust independent *t*-test using 1000 bootstrapped samples and bias corrected and accelerated confidence intervals was used for continuous data that failed to meet parametric assumptions.¹⁷ Qualitative data were coded by the second author and then categorized into themes and subthemes by the first and second authors and content analyses were created where frequencies of themes and subthemes were calculated.¹⁸

RESULTS

Understanding contexts

Thirty-one EACD national coordinators responded to the first survey, providing information on service organization and delivery for disabled children, including changes over the last 10 years. Qualitative free-text information within the survey responses was provided by 27 of 31 national coordinators.

National coordinators from 9 out of 31 countries reported work in progress on development of services to assess and better meet their needs from a low baseline, challenged variously by culturally embedded stigma about disability, the effects of conflict and war, and institutionalization of unknown numbers of disabled children. Content

analysis of themes and key points from national coordinators responses are detailed in Table SII (online supporting information).

Professional and family response rates and demographics

Responses were received from 959 professionals from 32 countries and 731 families from 23 countries. Professional respondents, organization type, and family demographics are shown in Table I. Of professional respondents, 44% (424) were from countries that met the criteria for austerity, whilst 65% (475) of family respondents were from countries in austerity. Of family respondents, 45% (332/731) met the UNICEF criteria for severe poverty and 49% (361) had completely dependent disabled children.

Table I: Participant demographics

Professional respondents (n=959)					
Profession of respondent	Organization type by profession n (%)				
	Private	Public	NGO	Charity	Not stated
Doctors (n=205, 21%)	36 (18)	158 (77)	10 (5)	1 (0)	0 (0)
Nurses (n=22, 2%)	0 (0)	19 (86)	1 (5)	1 (5)	1 (5)
Allied health professionals (n=548, 57%)	168 (31)	308 (56)	53 (10)	16 (3)	3 (1)
Education workers (n=105, 11%)	23 (22)	67 (64)	9 (9)	2 (2)	4 (4)
Social care/welfare support (n=59, 6%)	8 (14)	33 (56)	15 (25)	3 (5)	0 (0)
NGO workers (n=9, 1%)	2 (22)	1 (11)	5 (56)	1 (11)	0 (0)
Other (n=8, 1%)	2 (25)	4 (50)	0 (0)	0 (0)	2 (25)
Not stated (n=3, 0%)	1 (0)	1 (0)	1 (33)	0 (33)	0 (33)
Austerity n (%)	Austerity				424 (44)
	No austerity				535 (56)
Family respondents (n=731) n (%)					
Survey completed by, n (%)	Parent carer				689 (94)
	Disabled young person				33 (5)
	Not stated				9 (1)
Location of respondent, n (%)	Big city				201 (27)
	Town				273 (37)
	Village				208 (28)
	Rural community				42 (6)
	Not stated				7 (1)
Sex of disabled child/young person, n (%)	Female				286 (39)
	Male				434 (59)
	Not stated				11 (2)
Age of disabled child/young person, average (SD)					11.8 (±7.2)
Austerity n (%)	Austerity				475 (65)
	No austerity				256 (35)
Dependency level of disabled child n (%)	Can care for themselves				86 (12)
	Can partly care for themselves				273 (37)
	Completely dependent on others				361 (49)
	Not stated				11 (2)
World Health Organization poverty indicators n (%)	≥4 poverty indicators				332 (45)
	<4 poverty indicators				390 (53)
	Not stated				9 (1)

NGO, non-governmental organization; SD, standard deviation.

Direct impact on families of cuts to services and welfare support

Direct impact on families' ability to buy food, heating, and pay water and other bills was reported by 73% (311/424) of professionals from countries with austerity and 55% (296/535) of professionals from countries with no austerity (Table II, $p<0.001$).

Indirect impact on families via cuts to the services they rely on

Professionals across all country groups reported cuts to services (598/959; 62%); requests from families for advocacy, for example, by providing a letter of support (486/959; 51%); increased waiting times for services compared to 3 years ago (416/959; 43%); and less time allocated to see each child compared to 3 years ago (473/959; 49.3%), with no significant difference between country groups ($p>0.05$, Table II). Changes to referral criteria to limit referrals in the last 3 years were reported by 40% of professionals overall (381/959), this being implemented more often in countries without austerity (229/535; 43%) than in countries with austerity (152/424; 36%, $p=0.022$). Worse working conditions in the last year were reported by 53% (513/959) of professionals overall; this was especially prevalent in countries with austerity (258/424; 61%) compared to those with no austerity (255/535; 49%, $p<0.001$). Local quality targets for disabled children were reported to be met by 64% of professionals overall (616/959), more often in countries without austerity (367/535; 69%) than in countries with austerity measures in place (249/424; 59%, $p=0.008$).

Table II: Survey responses from professionals on direct and indirect impact on families of cuts to services

Indirect impact criteria	Professionals % (n)			p
	Austerity (n=424)	No austerity (n=535)		
Changes to referral criteria to limit referrals reported	36% (152)	43% (229)	0.022 , $\chi^2=5.29$	
Local quality targets for disabled children reported to be met	59% (249)	69% (367)	0.008 , $\chi^2=7.08$	
Worse working conditions reported	61% (258)	49% (255)	<0.001 , $\chi^2=15.99$	
Increased waiting times in last 3y reported	45% (189)	42% (227)	0.494, $\chi^2=0.47$	
Requests for advocacy reported, e.g. letter of support	51% (218)	50% (268)	0.660, $\chi^2=0.19$	
Cuts to services reported	65% (275)	60% (323)	0.215, $\chi^2=1.54$	
Direct impact on families of cuts to services reported	73% (311)	55% (296)	<0.001 , $\chi^2=31.17$	
Less time to see each child reported	50% (210)	49% (263)	0.865, $\chi^2=0.03$	

Results in bold type reach significance $p<0.05$.

Access to and experience of health services

Worsening quality of services compared to 3 years ago was reported by 91% (667/731) of families overall, with no difference between those from countries with and without austerity, or between families in severe poverty or not ($p>0.05$, Table III). However, more families with disabled children who were not completely dependent (337/359; 94%) reported worsening quality of services compared to families with completely dependent disabled children (320/361; 89%, $p=0.009$). Increased waiting times for services were reported by a total of 39% (288/731) of families (Table III). Professionals from countries without austerity reported a higher mean increase in waiting times by 5.3 weeks compared to those from countries with austerity ($p=0.04$, Table IV).

More difficult access, compared to 3 years ago, was reported by families: to therapists (379/731; 52%); to support in education (331/731; 45%); to social care support (390/731; 53%); and to welfare support and benefits (415/731; 57%) (Table IV). Fewer families reported more difficult access to voluntary organization support (240/731; 33%) and to peer support (166/731; 22.7%). More professionals from countries with austerity reported more difficult access to support in education (241/424; 57%, $p=0.002$), social care support (246/422; 58%, $p=0.001$), and welfare support (272/424; 64%, $p=0.023$) than those without austerity (254/424; 47%, 258/424; 48%, and 310/424; 58% respectively, Table IV). Additionally, more families from countries with austerity (290/475; 61%) reported more difficult access to welfare support and benefits than families from countries without austerity (125/256; 49%, $p=0.005$). However, families from countries without austerity reported access to social care support was more difficult (148/256; 58%) than those from countries with austerity (242/256; 51%, $p=0.039$).

How well needs have been perceived to have been met over time, compared to 10 years ago

All family groups reported their disabled children's health, education, and social care needs to be less well met than 10 years ago, with the exception of families in severe poverty, who reported a slight improvement in support in education (Table IV), although this did not reach statistical significance ($p=0.311$). Families with completely dependent disabled children reported their social care needs to be significantly less well met compared to 10 years ago than families with disabled children who were not completely dependent (Table IV, $p=0.039$). Professionals from countries with no austerity reported overall improvement in how well health, education, and social care needs had been met compared to 10 years ago, whilst professionals from countries with austerity measures reported a decline (Table IV). There was a statistically significant difference between responses from professionals from countries with and without austerity in the mean change in how well health needs ($p=0.015$) and social care needs ($p=0.002$) were reported to be met, compared to 10 years ago.

Table III: Survey responses from families on quality of services and waiting times

Families % (n)	Austerity (n=475)	No austerity (n=256)	p	Completely dependent disabled child (n=361)	Disabled child not completely dependent (n=359)	p	Severe poverty (n=332)	Not severe poverty (n=390)	p
Worsening quality of services reported compared to 3y ago % (n)	92% (437)	90% (230)	0.125, $\chi^2=2.35$	89% (320)	94% (337)	0.009, $\chi^2=6.86$	91% (302)	92% (357)	0.793, $\chi^2=0.07$
Increased waiting times in last 3y % (n)	38% (180)	42% (108)	0.308, $\chi^2=1.04$	39% (142)	39% (141)	0.939, $\chi^2=0.01$	38% (127)	41% (159)	0.449, $\chi^2=0.57$

Results in bold type reach significance $p < 0.05$.

DISCUSSION

Summary of the main findings

Whilst this study set out to examine the impact of austerity on the experiences of families and professionals, one of the main findings was that regardless of austerity, families with disabled children and professionals caring for them across Europe reported that care has declined in recent years.

Professionals working with families with disabled children reported cuts to services, increased waiting times, and less time allocated to see each child compared to 3 years ago. More than half of professionals reported worse working conditions in the last year. Worse working conditions were significantly more commonly described by professionals from countries in austerity than from countries without austerity, as were observations of direct and indirect impact of austerity cuts. Quality targets for services for disabled children were more likely to be met in countries without austerity than in those where such measures were in place. This is despite professionals in countries without austerity reporting a higher mean increase in waiting times compared to 3 years ago than professionals from countries with austerity. It is noteworthy, however, that professionals in countries without austerity were more likely to report changes in referral criteria to limit referrals than professionals in countries with austerity, which may be a factor in enabling quality targets to be met.

More than nine in every ten families reported worsening quality of services for their disabled children compared to 3 years ago, regardless of austerity. Most families reported their disabled child's health, education, and social care needs to be less well met than 10 years ago. Families with completely dependent disabled children reported the worst experiences, in terms of how well their needs were met compared to 10 years ago. Families from countries with austerity cuts reported more difficult access to welfare support and benefits. Whilst more professionals in countries with austerity reported worsening access to social care support than 3 years ago, the views of families were the opposite: families in countries without austerity reported the worst access to social care support.

Comparison with other literature

Previous studies evidence variation in outcomes for children linked to socio-economic factors and austerity cuts,¹⁻⁵

as well as variation in aspects of care for disabled children.¹⁹ Despite systems being in place in England to collect data at the point of care about the multifaceted needs of disabled children,¹⁰ these have not yet been widely adopted in most European countries, so there is still no source of internationally comparable data about the needs or experiences of disabled children and their families.

In 2013 as part of the Europe 2020 strategy, the European Commission made a recommendation to invest in children to break the cycle of disadvantage.²⁰ Despite UK mortality rates for infants and children being worse over time compared to other European countries,²¹ calls by researchers, professional groups, and non-government organizations for children to be prioritized in all policies²² have not yet been acted upon in all countries.

In many European countries, especially in the East, conceptualization of disability is shifting from a purely medical model to embrace the biopsychosocial model of the World Health Organization's International Classification of Functioning, Disability and Health.⁷⁻⁹ These changes are likely to shift the perceptions of families and professionals about service availability and quality. Reports from these and other countries reporting no austerity were generally more positive than from countries reporting austerity.

The Equality and Human Rights Commission has a statutory obligation to regularly report on progress across England, Scotland, and Wales on equality and human rights progress for disabled people.²³ In their 2017 report, there is evidence not only of lack of progress, but that things have gone backwards in some areas, leaving disabled people more disadvantaged in UK society, especially those with learning disabilities and mental health conditions.²⁴ More families that include a disabled person live in poverty, and have inadequate access to mental health services, adequate housing, and transport to enable their participation in society and achieve their hopes and dreams. The UK, along with many other countries, has signed up to the UN Conventions on the Rights of the Child and Rights of Persons with Disabilities,²⁵ which was designed to protect the equal rights to the best outcomes for disabled people. However, the Equality and Human Rights Commission 2017 report concludes that, 'It is a badge of shame on our society that millions of disabled people in Britain are still not being treated as equal citizens and continue to be

Table IV. Increase in waiting times, access to services, and change in how well needs were reported to be met by services, compared to 10y ago, as reported by professionals and families

	Professionals				Families			
	Austerity (n=424)	No austerity (n=535)	Austerity (n=475)	No austerity (n=256)	Completely dependent disabled child (n=361)	Disabled child not completely dependent (n=359)	Severe poverty (n=332)	Not severe poverty (n=390)
Mean increase in waiting time in number of weeks (SD)	12.4 (22.8)	17.7 (25.6)	17.9 (25.7)	25.7 (33.8)	19.7 (27.6)	21.6 (30.51)	17.8 (22.9)	23.2 (33.4)
More difficult access reported, compared to 3y ago, to % (n):	52% (222)	47% (249)	47% (244)	53% (135)	53% (193)	50% (180)	52% (174)	52% (202)
Therapists								
Support in education	57% (241)	47% (254)	48% (226)	41% (105)	48% (174)	42% (151)	48% (158)	44% (170)
Social care support	58% (246)	48% (258)	51% (242)	58% (148)	53% (192)	52% (188)	52% (174)	54% (211)
Welfare support and benefits	64% (272)	58% (310)	61% (290)	49% (125)	56% (203)	57% (204)	57% (188)	57% (222)
Voluntary organization support	29% (121)	24% (130)	34% (160)	31% (80)	31% (113)	35% (124)	31% (103)	34% (133)
Peer support	17% (72)	19% (103)	21% (100)	26% (66)	23% (82)	23% (82)	23% (75)	23% (89)
Change in mean score/100 over last 10y in how well needs reported to be met (SD)								
Health	-3.3 (26.3)	1.2 (26.6)	-2.56 (33.08)	-4.52 (34.6)	-4.61 (35.04)	-1.75 (32.0)	-0.97 (32.7)	-5.08 (34.3)
Education	-0.56 (28.5)	2.3 (27.5)	-1.28 (32.8)	-0.26 (36.1)	-3.25 (32.9)	1.65 (34.6)	1.07 (33.9)	-2.31 (33.8)
Social care	-6.4 (27.3)	0.5 (26.8)	-7.04 (29.2)	-3.21 (32.0)	-8.70 (31.3)	-2.88 (29.0)	-4.59 (29.0)	-6.85 (31.1)

Results in bold type reach significance $p < 0.05$. SD, standard deviation.

denied the everyday rights non-disabled people take for granted, such as being able to access transport, appropriate health services and housing, or benefit from education and employment'.²⁴

Limitations

A tight timeline and budget were set for completion of this work. This was not an epidemiological survey. Only those with internet access could be reached with the surveys. Dissemination of the survey links was variable between countries and depended on the enthusiasm of those sharing the links, resulting in different response rates between countries. The surveys could not capture the needs or situations of those disabled children living in institutions or who receive no care. Findings must be interpreted with caution.

Strengths

The strengths of this study are that it reached a diverse range of families and professionals across many European countries, having used translation to numerous languages to remove barriers to participation. Response rates were good in the available time from families and professionals compared to previous electronic surveys (International Cerebral Palsy Society, personal communication 2016). The quantitative findings are supported by the themes emerging from qualitative data.

Implications for the future

There is not a simple or single solution to improving equality of outcome opportunity for all disabled children across Europe; rather a stepwise and multipronged approach is required. A good start would be to embed data collection about the multifaceted needs of all disabled children at the point of all care regardless of setting. Needs made visible are more likely to be met. Not all solutions cost money; 'can-do' positive attitudes and creative problem-solving cost nothing but can make a significant positive difference to the experiences of disabled children and their families.^{14,26} Education and training are priorities for

the International Alliance of Academies of Childhood Disability. Solutions require resources and political will. The EACD joins UNICEF and others in the call for the needs of children to be specifically embedded in all policies at all levels in all countries, including the complex needs of those most vulnerable. Justice is required to fulfil our obligations to disabled children, enshrined in the United Nations Convention on the Rights of the Child²⁷ and United Nations Convention on the Rights of Persons with Disabilities.²⁵

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1: Survey for EACD National Coordinators and other identified national leads.

Appendix S2: Content of survey for professionals working with disabled children, young people, and their families.

Appendix S3: Content of survey for families with disabled children and young people.

Table SI: Respondents by countries in austerity and not in austerity.

Table SII: Content analysis of the themes and categories that emerged from the comment sections of the survey sent to EACD national coordinators.

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