



British Association for Community Child Health

Impact of Austerity Measures on families with Disabled Children: Survey of BACCH and BACD members and Child Development Team leads November 2014 and January 2015

Counting the Cost

Contact a Family's Counting the Cost 2014 survey (based on responses from more than 3500 families) show a sharp rise in families with disabled children going without the basics such as food, heating and days out as a family since last researched in 2012¹.

- Nearly a third are also going without specialist equipment, adaptations or therapies.
- A third (33%) are worse off as a result of benefit changes.

The findings also show the impact on family health:

- 22% say their child's condition has worsened because of going without
- Almost half of families are suffering ill-health because of going without
- Over 90% are suffering anxiety and stress due to debt

To get a different perspective on the direct and indirect impact of austerity measures on families with disabled children, an online survey link was sent by email on 20 November 2014 to all members of the British Association for Child Health, the British Academy of Childhood Disability and Child Development Team leads, previously identified as part of a large, capture-recapture exercise². Findings were analysed on 25 November 2014. In order to get more specific information, a second survey was sent out 8 January 2015 and analysed 16 January 2015. A total of 134 responses were received from all four nations and a spread of regions.

BACCH and BACD Survey: Impact of austerity measures on families with disabled children November 2014

Survey results

134 responses were received.

Regional representation	
Region	Responses
Scotland	10
Northern Ireland	4
Northern	28
North West	8
Yorkshire	8
Mersey and Cheshire	10
Trent	4
Wales	4
West Midlands	9
Oxford	8
East Anglia	7
Thames North East	5
Thames North West	9
Thames South East	6
Thames South West	3
Wessex	3
South West	5
Not specified	3
Totals	134

Regional representation

1. Have you experienced direct impact on families of austerity measures e.g. impact on ability to buy food, heating and pay water and other bills?

	Percentage
Yes	65%
No	34%

Reported direct impact on families included:

- 34% reported Housing issues / evicted / forced to move due to bedroom tax / inadequate housing / made homeless
- 12% reported transport costs preventing access to services / medical appointments
- **8%** reported some families unable to afford water bills where disabled child had high water usage for medical reasons
- **7%** reported insufficient food / referred to food bank
- Other reported **direct impacts** on families included:
 - Families no longer able to afford swimming lessons and other activities for their children
 - Parents going without so children can have basics
 - o Unable to afford adequate heating, including in one case for a dying infant
 - Anxiety / mental health issues for parents due to financial pressures
 - Unable to afford high cost hospital retail outlet food when child in hospital
 - o More families declined for Direct Payments
 - o Disability Living Allowance downbanded
 - Unable to pay household bills due to financial pressures

- Parents having to work longer hours, more exhausted, struggling to get to medical appointments for child
- Families with disabled children rarely in a position to fight poor commissioning decisions and low on government agenda
- Single mother of two under 5's, one with severe autism, asked by job centre to return to work rather than claim benefits
- Children of highly mobile families are most vulnerable
- Increase in requests for Disability Living Allowance from families of children with lower levels of impairment due to financial pressures
- Poverty already a massive factor in Wales and all the worse with austerity
- Families are demoralised, however unable to do much as they are so busy taking care of their disabled children.
- Our parent and carer support group had to fold when social work withdrew resource worker post and funding for mobile creche. Also lowering age of youngest child when parent has to go onto jobseekers to 5 years is a particular issue in Scotland, as children start school later: between 4 and a half and 5 and a half - so parent is challenged by all the demands of Job Seekers Allowance whilst child is only in nursery half days, needing to be picked up, and parents risk benefits sanction
- The point was also made that more families are directly affected by austerity measures but do not discuss this during consultations with paediatricians
- 2. Have you been asked to provide support to families e.g. letter of support?

	Percentage
Yes	82%
No	18%

Paediatricians reported being asked to write **letters of support** regarding the following issues affecting families with disabled children:

- 48% had been asked to support rehousing to better meet needs of disabled child / children
- **29%** had been asked to explain why a severely disabled child needs their own bedroom and should be exempted from bedroom tax
- 12% had been asked to support appeals for Disability Living Allowance
- Other reasons why letters were requested included:
 - To water companies to explain high usage on medical grounds
 - To access more specialist educational provision / more support at school
 - To justify need for specialist equipment
 - To ask for charitable funds for specialist equipment not provided by statutory services
 - To request reduction in household bills
 - In support of need for short breaks / respite, due to cuts in social care budgets
 - To keep Blue Badge (due to change in threshold)
 - To appeal removal of funding for transport to special school

3. In your service, have you experienced the impact of austerity measures on services with % cuts made across the board?

	Percentage
Yes	79%
No	21%

Reported **indirect impact** of austerity measures on families with one or more disabled child, with cuts in services that they need to access, included:

- In addition to the above, of those who answered a further question about the specific % of cuts in their services:
 - 6% reported >20% cuts, with a further 6% reporting 20-25% cuts coming from April 2015
 - **37%** reported 10-20% cuts
 - o 29% reported 5-10% cuts, one of which reports 20% cut to come from April 2015
 - **11%** reported <5% cuts
 - **14%** reported no cuts
 - o Only one respondent reported service expansion
 - Comments included:
 - We are constantly having posts reduced or not readvertised
 - Our specialist service had some agreements to expand services, which the Trust is now blocking due to financial difficulties. Posts are frozen
 - Non-replacement of retiring staff grades to reduce medical establishment by 20%
 - 25% cut in service budget coming in next financial year
- 72% reported longer waiting times for paediatric disability, community paediatric and therapy appointments with increasing workloads at the same time as cuts in services
 - **49%** reported increased wait to 8-18 weeks
 - o 26% reported increased wait to more than 18 weeks including:
 - Increased wait to ~ 5 months
 - Current waiting times in most patches are 20 weeks+ to get to first appointment, not completing assessment
 - Some children waiting up to 23 weeks to see a physiotherapist
 - Routine new patient wait = 26 weeks, review >26 weeks
 - Increased wait to 35 weeks
 - Wait of >8 months to regional neurology and cardiology services
 - Wait of about a year for an autism assessment
 - Wait of >2 years for autism assessment
 - Increased wait for those with complex disabilities and cerebral visual impairment to > 2 years
- Other specific comments included:
 - Increased waiting times for Occupational Therapy, Autism Assessments, services are not provided and threshold for accepting referral is higher

- A 2 year wait to diagnosis when the referrer suspects severe cerebral visual impairment risks an emotionally damaged child at risk of educational failure and mental health issues
- Children depending on Gastrostomy tube feeding who need change of tube under General Anaesthetic seem to wait until it's an emergency (in our regional children's hospital). They go on a waiting list but it could be a year before surgery unless the tube completely fails. When a child needs inpatient transfer to the Regional hospital there is always major difficulty in finding a bed leading to increased pressure on children and families, as well as on the referring clinician.
- Our ASD patients waiting more than a year for getting diagnosis; Children with ADHD are not getting any psychological input or therapy
- Child Development Centre services are markedly reduced, majority of staff with long standing service have been reallocated, resigned or gone on sick leave. I have been forced to reduce my clinic time spent with children with complex and multiple needs
- Many reported posts frozen / not replaced leading to reduced capacity in medical, nursing and therapy services
- In our community paediatric team we have major gaps in staffing. This is partly because of lack of funding for replacements and locums but also recruitment issues. In one area of our Trust this is reaching crisis point with no assurance from managers that any funding will be available. Our Trust is experiencing cuts to all areas of service with restricted use of Bank and Agency staff and some surgeons being asked to reduce PAs and cut lists. Paediatrics, especially community paeds, is not high on the Trust list of priorities. Acute paediatrics has not had any cuts in medical staffing but that is because there has been almost no expansion over the past 15 years so there is nothing to cut.
- Increased gap in time to diagnosis for autism spectrum disorders and attention deficit disorders as compared to diabetes, cancer, cystic fibrosis etc.
- One responded: unable to respond as department not fully staffed as unable to fill posts

Have the goalposts been changed in your service or services that you know about in your region, e.g. clock stopped on 18 week referral to Treatment rule, referrals sent back to GPs, etc. Please specify. To this specific question:

- **30%** of respondents report that they are having to send referrals back to GPs or refuse referrals as no capacity to see all the referrals
 - In one service, managers triage referrals with no medical input and return to referrers to disguise pressure on services and waiting times
- 39% respondents reported raising threshold for access to their service
- 5% reported 'clock stopped' on 18 week rule
- 13% respondents reported increased pressure on review slots, shortened time to review patients or pressure from managers to discharge early. This includes reduced time to see and manage those with complex disabilities. Other services report that in order to see new patients within 18 weeks, review patients have to wait or are not seen, including in the therapies.

- There are many comments about the squeeze on review caseloads i.e. assessments get done eventually, but then there is insufficient resource to provide an adequate service or support ongoing for disabled children, young people and their families.
- There are no targets set for review patients, so they do not count in the scheme of things
- Many respondents report discontinuation of complete services, including sleep management, dyspraxia, behavioural issues where there are no neurodevelopmental concerns
- A child with spastic diplegia was referred to Nottingham for management of spasticity however assessment could not take place because of funding issues.
- For those with Autism Spectrum Disorders, once diagnosed, very little support other than parental education which parents find useful but not enough.

In response to the question: Is your service missing targets in the last one year?

- **79%** respondents report missing NICE or SIGN guideline targets for assessments e.g. of those with ?Autism Spectrum Disorders and ?Attention Deficit Disorders.
 - **5%** report ASD assessments take >2years
 - **10%** report ASD assessment take > 1 year
- Many report reductions in MDT assessments to save costs
- No longer able to adhere to the level of quality of assessments specified in SIGN and NICE as the level of staffing has dropped in many specialised children's services disciplines
- Many services report difficulties in providing reports for the transfer of children and young people from statements of special educational needs to Education, Health and Care plans. Some report that this is impossible as insufficient resources and also not possible to attend all of the review and planning meetings.
- Unable to offer review appointment within 6 weeks of diagnosis of autism spectrum disorder as per NICE guidance

92% reported impact on paediatric services of raised thresholds for referral to therapies, CAMHS, Educational Psychology, Specialist Support in Education, Social Care support and voluntary services cut or withdrawn.

Some specific comments include:

- Paediatricians having to take on additional support roles for families due to cuts in the wider team
- Child and Adolescent Mental Health Service (CAMHS):
- Many reported increased thresholds for Child and Adolescent Mental Health Services (CAMHS) / reduced capacity in CAMHS / decommissioning of CAMHS for some groups / up to one year + wait for intervention with CAMHS impacting on community paediatric and paediatric disability services with no increased capacity to manage additional workload
- CAMHS services are very stretched and it is hard to get referrals accepted.
- CAMHS have the most efficient gate keeping methods of any service I have ever dealt with i.e. most referrals returned as unsuitable. For clinical psychology, CAMHS or any sort of behavioural service, all are overloaded so the 'default'

response seems to be to try and deflect the referral to another service - by returning to the referrer. As a paediatrician this means 3 times the amount of admin work and extreme frustration trying to access help for families.

- CAMHS non-existent, schools have to pay for educational psychology and are reluctant
- CAMHS have lost a specialist Occupational Therapy post. These changes have not just happened in the last 1 year but progressively since the start of the recession and we are expecting it to get progressively worse. 2015/6 is going to be very difficult and our Trust has to find £25m of savings.
- Access to CAMHS very limited and is primarily for those where a psychiatric diagnosis is likely. Very little access to clinical psychology for support around behaviour. Joint disability service also rejects more referrals than it accepts.
- Services for family support and child mental health have been contracted meaning these services set higher and higher thresholds for involvement
- Every service particularly CAMHS have new criteria for referral and their waiting times are also long
- Access to CAMHS services worsened; CAMHS providing a very poor services now
- CAMHS, Portage and parenting programmes harder to access
- Young people with various behavioural problems been pushed from CAMHS to paediatricians, lots of young people been sent out of area for second and third appointments. Many children ending with school refusal, and others with school exclusion.
- Children with self-harming behaviours not accepted by CAMHS
- Our Children's Learning disability team who supported families of children with severe Learning Difficulties was reduced by 50% meaning the waiting list for an assessment can be many months
- The issue is about who is supporting families for children with behaviour issues around parenting everyone is viewing this as someone else's job.
- More referrals are being rejected by child psychiatry and specialised children's services.
- · Access to mental health services for behavioural advice is also inadequate
- Child and adolescent mental health services are accepting fewer referrals sending back rejections, with leaflets about voluntary agencies to which they suggest I should direct patients.

• Therapies

- Physiotherapy no longer see children with Down's Syndrome
- Shorter therapy input after assessment, even those with four limb cerebral palsies being discharged by therapies with no ongoing input despite ongoing needs
- Many report Speech and Language Therapy provision has reduced drastically.
- Access to assessment of sensory issues with by Occupational Therapist for those with Autism Spectrum Disorders stopped
- Previously we were employing experienced therapists band 6/7 but the number of senior therapists have been significantly decreased. More worrying is dietetic service with loss of all band 7 posts and appointment of band 5 ie newly qualified dieticians who may or may not have experience of managing children, and will be working as independent practitioners in a community setting. We are raising this

with the trust as a specific risk. In addition staff at lower bands have always moved on to better paid posts which leads to a lack of continuity which families find hard.

· Generally cuts are in every area of the service

Nursing

- Reduced special school nursing staff
- Downgrading of special school nurses
- Reduced Children's Community Nursing teams
- Loss of specific community nursing roles eg specialist Health Visitor, Asian link nurse, hard to get disabled children's team Social Work assessment
- Within our Community Children's Nursing (CCN) team there is low morale as cost saving have led to one of our matron posts being cut and the CCNs are now line managed with therapy services, the matron concerned is taking early retirement. It is not clear as yet if this will affect our service but I predict that we will find it hard to retain staff.
- Over the years the establishment of special school nurses has been reduced making it difficult for them to do casework outside the school premises.
- Healthy Child Programme re-commissioned so school nurses move away from community paediatrics into a different Trust. Successful (NHS) bid £1.5M less than the current HV/SN budgets so anticipate significant cuts in 2015/16.
- Loss of specific community nursing roles e.g. specialist Health Visitor, Asian link nurse

• Specialist support in Education

- Many reports of cuts to Educational Psychology Services
- Cuts in Education, including specialist educational provision, Educational Psychology services, early years teachers and Portage programmes
- Specialist support within schools increasingly hard to access, results in issues coming to health that would not have otherwise.
- School are trying to refer directly to community paediatrics to avoid educational psychology targets.
- Many children with significant needs cannot be accommodated in special nursery, children with special needs are passed on from one service to another as almost all services are affected.
- Access to educational psychology for local services has been inadequate for a long time.
- Specialist support within schools increasingly hard to access, results in issues coming to health that would not have otherwise.
- Behaviour support has disappeared so more children are being referred who otherwise would have been managed appropriately in school. This then leads to families expecting diagnosis of a neurodevelopmental problem when not always appropriate
- In some areas educational psychology no longer expect to see children with disability.

Social Care

• Social care for these children is awful and getting worse due to lack of resources.

- Very little respite or help. Lack of action when Child Protection issues, all because they are so short staffed.
- More social work emphasis on child protection and less support for disability
- Social care have increased the threshold to accept cases for child protection and disability.
- The worst area in my opinion is children's social care. It's very difficult to get and keep an allocated social worker. Respite care packages have been withdrawn pending reassessment and then not reinstated. Parents have expressed concerns about poor quality respite care from private agencies, and withdrawn children as a result: 'they just park him/her in front of video games, instead of taking them out and doing activities, I might as well just do that myself.'
- Social care for these children is awful and getting worse due to lack of resources. Very little respite or help. Lack of action when Child Protection issues, all because they are so short staffed.
- In some areas the children and disability social work service has been disbanded with children being picked up (or often not) by staff with no specialist knowledge of disability.
- Thresholds for social work children with disability teams becoming involved have increased over last few years, and social work resource worker posts in child development centres withdrawn.
- Hard to get disabled children's team Social Work assessment
- Many reported reduced support for families from social care, reduced short breaks / respite and reduced support with transport to appointments

• Voluntary Services

- Many voluntary services cut
- ABCD Cymru an NGO providing support and advocacy to disabled children from ethnic minority groups closing down after 20 years because of local authority and Welsh government cuts to core funding. Highly valued by the families
- Lots of the charity support services have folded.
- Social work funding ceased for some voluntary agencies such as one supporting the Chinese community (which was about to start a parent and carer support group for Chinese families affected by autism).
- In Wales lost a number of NGOs and local government youth services completely
- Cuts to voluntary services and programmes that were working well with good evaluation of positive outcomes e.g. Face2face service of peer support for parents

Without being asked or prompted:

- **24%** spontaneously reported low staff morale in child development, disability and community paediatric teams
- **34%** spontaneously reported staff downgraded across the board, especially impacting on therapies, year on year 'cost efficiencies' of up to 25%, reduction in administrative and secretarial support leading to errors and inefficiencies
- **15%** spontaneously specifically report commissioning inefficiencies, gaps and disasters, including whole services decommissioned then recommissioned with gaps, Child Development Teams fragmented into five different organisations, money-wasting

tendering processes, lack of commissioning for end of life care and loss of organizational history

- Many reported that Multidisciplinary assessments are increasingly difficult to carry out. More resources needed for this sort of assessments. Doctors are now not attending multiagency meetings unless absolutely necessary. Feedback from other services are of poorer quality as well, making assessments more difficult to conclude
- 'It is very distressing to be working in a service which used to function well and now seems to be in chaos'
- Team members reporting stress
- With increasing number of children with disability, there has been no expansion of service accordingly
- We have cheap housing so huge influx because of bedroom tax
- Other reported **indirect impacts** of austerity measures on families with one or more disabled child resulting from cuts in services included:
 - A Royal College of Paediatrics and Child Health review of one service recommended that four more doctors were required, but no funding to recruit
 - Those in hybrid jobs being pulled in to acute paediatric services to the detriment of services for the disabled and vulnerable
 - Increase in parental expectations due to Children and Families Act and Code of Practice (SEND reforms) but inadequate funding allocated to health for implementation of the reforms. Paediatricians barely able to sustain child protection and looked after children rotas due to cuts in services and having to reduce clinics in special schools
 - Reduced standards of care
 - Funded study leave suspended
 - Reduction in preventive services
 - Increasing complexity of caseloads
 - o Increase in complaints
 - Agency budgets displacing the needs of the child as central focus of attention in inter-agency meetings
 - Cuts to Early Bird parent training programmes for those with children diagnosed with autism spectrum disorders
 - Loss of Keyworking schemes that were working well
 - o Increased difficulties in accessing specialist equipment and getting this funded
 - Closure of children's centres
 - Cuts in cleaning
 - Large influx of non-English speaking immigrants with disabled children needing services
- Very few paediatricians are prepared to speak out to the media about these issues, because they fear for their jobs
 - E.g. "I am being blamed for the reduced morale of the staff and nervous breakdowns and if I ...speak to the media.. I am sure to lose my job. Extremely sorry for being selfish".

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Discussion

65% of respondents reported witnessing direct impact on families of austerity measures. This is likely to be **a significant under-representation of the reality**, as many families would not volunteer information about their personal circumstances during paediatric consultations or to their therapists and teams. The Counting the Costs survey done by Contact a Family, of direct reports from families, is likely to be much more representative of the **direct impact** on families.

The new information that the BACCH and BACD survey brings is that **almost 80%** of those who completed the survey reported **cuts to services for disabled children and their families** and **over 80% of paediatricians are being asked to write letters of advocacy**, mostly about housing and the impact of the bedroom tax, also about downgrading in level of Disability Living Allowance awarded and for a range of other issues, including seeking charitable funding for equipment or services that were previously provided by statutory services.

49% who responded about the specifics of percentage cuts report cuts of more than 10% and up to 25% across the board in services for disabled children and their families. 72% report an increase in waiting times for initial appointments with the paediatrician and or with therapists, which for families with disabled and potentially disabled children is only the very beginning of a long journey to access all of the right services with all the specialists required to address their multi-faceted needs. 26% report increase in waiting times to over 18 weeks, which is the referral to treatment target set for the NHS in general and some services report waits of more than two years to achieve a diagnosis e.g. of autism spectrum disorder, because that is how long it takes to see the specialists required to make this assessment. Almost 80% of those responding to the specific question about whether their service is meeting timeline guidance set by the National Institute for Health and Clinical Excellence (NICE) said that they are not able to meet these timelines. Other services report waits of **more than two years** to see specialists in complex disabilities and cerebral visual impairments, which are completely unacceptable waiting times to access the right assessments, treatments, care, support and information. Why should disabled children and their families have to wait these unacceptably long times to get the right assessments and treatments? Their children's conditions are likely to become more complex the longer they wait and be more difficult to manage, ultimately costing services more, including in out of area appointments and placements.

In some services, the **goal posts are being moved in order to disguise waiting times**, with **30%** respondents reporting that referrals were being returned to General Practitioners, including by non-clinicians and a further **39%** reporting **that thresholds to access services had been raised** as they were unable to meet current demands. In addition, **92%** of respondents reported **negative impact on paediatric services for disabled children and young people due to raised thresholds to access other services** that the children and young people needed. This results in paediatricians being left to try to manage issues beyond their competence, for example complex behavioural and emotional issues that need assessment from the Child and Adolescent Mental Health Services (CAMHS) and children and young people in need of hands on therapies, nursing care, support in education, short breaks and social care to keep them safe and optimally supported.

This is all at a time when parental and family **expectations** are at an all time high, due to the Children and Families Act (2014) and the new Code of Practice underpinning the reform of the Special Educational Needs and Disability assessment process, which is designed to be child and parent focused and bring all involved in their care and support together to set clear objectives with measurable outcomes.

It is known that disabled children and young people are amongst the most vulnerable in our society and are at higher risk of early death than children and young people who are not disabled³⁻⁴. The Chief Medical Officer in her special annual report called for better data about disabled children and young people⁵ and the 2013 UNICEF report on the State of the World's Children highlighted the issues faced by disabled children globally⁶. The Marmot report called for a fairer society, reduced health inequalities and opportunities for better health for all children, especially those most vulnerable⁷.

A reduction in services for disabled children and young people of the magnitude reported in this survey is an indictment of our society, of the unintended fall-out of reorganisations in the NHS and of the differential impact of austerity measures on those who are most vulnerable of all, namely, disabled children and young people.

Service reductions for this vulnerable group will inevitably lead to:

- An increase in premature deaths that could have been prevented
- Delays in diagnosing conditions for which there is evidence that early intervention makes a positive difference
- Increased risk of complications where timely identification and intervention could have made a positive difference
- Increased use of emergency services, emergency departments and in patient admissions for disabled children and young people whose families are not able to access proactive, timely healthcare for them
- Parents not being as well supported associated with an increase in their own morbidity, both physical and mental
- More young people presenting with complex emotional, behavioural and mental health issues that might have been prevented or at least better managed had they had access to appropriate assessment, diagnosis and treatment sooner
- More young people going off the rails for want of the right support
- More crimes, more detentions, more imprisonments.

The BACD and BACCH very strongly urge everyone who has any influence to:

- **STOP the cuts** to services for disabled children and young people
- Mandate prospective data capture at the point of clinical care, using the terminologies set agreed and build into the Children and Young People's Secondary Uses Dataset. This will allow the multi-faceted needs of disabled children and young people in our population to be clearly articulated and visible. Knowledge of population needs can inform intelligent planning across agencies for evidence-based services to best meet their needs
- **REINVEST and REBUILD competent, interagency teams** to prevent disabling conditions where possible and where it is not, to identify them early so that appropriate management and support can be put in place, informing and engaging with families. Teams need sufficient capacity to meet the increasingly complex needs of all disabled

children and young people equally, giving them the best chance of achieving the best possible outcomes in health, wellbeing and life opportunities that matter most to them.

Karen Horridge, Chair, British Academy of Childhood Disability Gabrielle Laing, Chair, British Association for Community Child Health

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