

Report to the BLF Awards for All Wales

Walking with Us – Project Number 0010317065 January – April 2018.



“Walking with Us” is a scoping exercise that reached 154 adults who care for disabled children across Wales with the aim of giving them a voice that will inform the structure and delivery model of an ambitious 3 year project specifically created for the families of disabled children by the families of disabled children.

Awards for All funding was used to fund the design, promotion, hosting and facilitation of seven in-depth consultation workshops and a comprehensive online survey for parent carers across North, South, East and West Wales. Workshops were co-facilitated by experienced staff and parent volunteers, and held in venues and at times suitable to participants. Welsh interpretation was offered at each stage of the project.

The objectives of the project were to:-

- Identify the gaps in essential information families with disabled children face around services including education, social care, respite and finances.
- Tackle isolation through introducing families to others in their situation and involving them in the ground work of their future project.

This report is structured around the survey questions; with insights from the scoping workshops included throughout.

Summary of results

Statistics about parent carers consulted

We ran 7 scoping workshops across Wales, in the principal areas of Wrexham, Ceredigion, Cardiff and Powys. Most were in group sessions although one session was individual discussion. Total attendance was 41, of which 35 were parent carers and 6 were professionals. Of these 23 were new contacts and 18 repeat contacts.

The online survey was completed by 113 respondents (across this summary report, the sample size for each individual question will be stated as $n = \text{number of respondents}$). All Welsh principal areas but one (Torfaen) were represented, with Cardiff; Conwy; Rhondda Cynon Taf; and Powys having 10 or more responses each.

86% (65) of survey respondents agreed to provide demographic information. Of these:



- 91% are female, 9% male
- 94% are in the 25-64 age bracket
- 33% are single parent carers
- 14% consider themselves to have a disability
- 95% are White British; other ethnicities represented are other white backgrounds and Asian (Bangladeshi)
- 20% consider themselves to be a Welsh speaker (however no families chose to do the survey in Welsh, though this option was available).

Surveys at scoping workshops 30 parent carers completed surveys after the scoping workshops. The proportion in different demographic groups is similar to the online survey, with a higher percentage of men (5 out of 30 or 17%) but a slightly lower percentage of single parent carers (30%); those with a disability (11%) and Welsh speakers (11%). There was a slight increase in people of Irish and Other White ethnicity, the proportion of those attending the focus groups who were White British was lower at 86%.

112 parent carers answered the online survey question on their child's age; a number of these had more than one disabled child which makes 132 children in total. 16% were in the age group 0-5; 36% were aged 6-10; 36% were aged 11-15; 7% were 16-18 and 5% were over 18.

112 parent carers answered the question on their child's condition. Many parent carers cited more than one condition (hence the figures below add up to over 100%), this includes:

- 58% (65) have a child with autism or Autistic Spectrum Disorders
- 17% (19) have a child with learning disabilities
- 13% (15) have a child with ADHD
- 13% (15) have a child with cerebral palsy
- 13% (14) have a child with developmental delays
- 11% (12) have a child with epilepsy
- 8% (9) have a child with Down's syndrome
- 7% (8) have a child with mobility or muscle disorders
- 6% (7) have a child with sensory processing issues
- 5% (6) have a child with a visual impairment
- Other conditions or symptoms mentioned include: (many of these are mentioned in conjunction with another condition): dyspraxia, dyslexia, hypermobility, PDA, mental health issues, rare condition, brain disorder, diabetes, hearing impaired, undiagnosed, speech issues, PICA, anxiety, tics, Fragile X, hydrocephalus, FASD, behaviour issues.



In the scoping workshops, 42% of the 33 children mentioned had autism or autistic spectrum disorders, 18% had rare conditions, 12% had ADHD, 12% had learning disabilities, 9% had cerebral palsy and 9% were undiagnosed. Other conditions mentioned include mobility problems, Down's syndrome, epilepsy, developmental delays, dyspraxia, SLI, anxiety, hearing impairment, visual impairment, microcephaly, behaviour problems, brain disorders, digestive issues, attachment disorders, sensory problems.



parent carers' needs



Q4. Please tick the 3 main challenges or worries that you are facing at the moment regarding your child with a disability or additional needs. (n=112)

This question was answered by 112 parent carers. Table 1 below lists the % of parent carers who ticked each of the items in the list. The item picked by most parent carers is *Mental health and wellbeing for you and your family*, identified by 59% of respondents as one of their top 3 challenges. This is interesting because anecdotally, we hear that parent carers do not identify their own health and wellbeing needs. While it is possible that parent carers do not prioritise these needs, this survey suggests that they do identify them.

The second most frequently picked item was *Issues around your child's education*; followed by *Your child's behaviour*.

Table 1. Main challenges or worries

Challenges	% identifying in top 3 challenges
Mental health and wellbeing for you and your family	59%
Issues around your child's education	48%
Your child's behaviour	45%
Short breaks / respite	34%
Transition to adulthood	31%
Your child's sleep	27%
Your family finances	26%
Childcare for your child	18%
Healthcare for your child	17%
Social care and direct payments	9%
Legal issues	6%

Parent carers were given the option to use the box below this question to tell us more about their concerns. The comments don't mention any "new" issues that weren't listed in the survey question, but they may mention specific aspects of a particular issue such as transport to school, waiting lists, and isolation.



A number of parent carers took this opportunity to list the impact that their concerns were having on their life, which again confirms the mental health and wellbeing issues that families are facing.

This [Situation] is causing me severe depression as it's a never ending battle for every crumb of support. Anxiety is a constant state and our whole family struggles because our lives have to revolve around [child]

The next most common issue that parent carers wanted to expand on was education, followed by respite and finances. Frequently parent carers used this opportunity to explain the complex challenges they are facing.

School not meeting my child needs and battling to get any support as he is educationally not behind but emotionally he is struggling and now off school often as no support

I have been pushed from pillar to post with both Education and Drs to get my child in pathways for diagnosis. [...] My son has been out of education for almost a whole academic year [...] I now have a proposed statement and I am struggling and battling to get it right for my child. I need assistance greatly.

In addition a number of parent carers specifically mention the fact that there's not enough services, that the services are inadequate, or that they don't know about what is available, and also their worries about their child's future.

I feel as though we aren't being checked up on enough, and that our struggles with behaviour aren't taken seriously at all. [...] We aren't sign posted enough where to turn for any help or second opinions. We also never get told about any activities ongoing for children and families with disabilities. As a result our family suffers greatly, especially with activities together which rarely happen anymore. His sister never gets any attention as I'm constantly having to deal with his behaviour.

my son has not received any support at all, and is deteriorating in all areas of life. He's been seen by schools EP, ASD TEAM+Neurodevelopmental Service all outlining he needs OT and Behaviour support yet no support has been given! and i am soo frustrated that i cannot find anyone to help me

The future is terrifying. Children's services and school have been wonderful but when we lose both I don't know how we will cope.





In many cases, the detailed comments added by respondents make links between the different issues, e.g. finances or (lack of) respite care affecting health and well-being; or lack of education provision affecting ability to work and therefore finances.

Mental health is affected by the constant fighting parents have to go through. We've had to go to tribunal to get DLA, we are fighting school for support.

OT took more than 4 years to get a diagnosis.....we spend our life fighting everyone for help that should be put in place without asking.

My son has very challenging behaviour and we are mostly housebound now, we are seeking the possibility of medication, but of course it's a process that like everything is taking forever, as it the provision of respite as in principal provision has been agreed but no provision of any sort has yet been forthcoming! Meanwhile as a family we are all suffering, become increasingly isolated [...]

I am concerned about the next level of education for her including transport, getting to and from college and access to one to one support as she gets older. Also worried about being able to adapt my house for her sufficiently as she's getting older and her needs change, the time all this takes to complete if you're lucky enough to get it. I'm also worried about what happens after she leaves high school and having someone to look after her when I have to work, does this mean I have to give up work ?? :(

I have to work full time, I'm a single parent, I have no idea if I could get any financial help which would let me reduce my hours. My child has been suicidal [...] Been referred to CAMHS who say it's related to 'high level of anxiety due to autism' and they can't offer her any help. Obviously all this has an impact on me and her siblings.

The scoping workshops highlighted similar challenges with behaviour, respite, sleep, education, support for siblings, transitions, and finances being the most frequently mentioned issues (in this order). The workshops also highlighted issues specific in particular areas. For instance parent carers in Wrexham mentioned issues around getting aids and adaptations (in particular special shoes) for their children, with long waiting lists and services not communicating with each other. In Powys, parent carers cited geographical issues around lack of and access to services, as this local authority has many rural or remote areas. This results in issues around school transport, and also with accessibility to appropriately trained external carers' (e.g. for respite), although often parent carers are not able to afford this option. Parent carers made a link between school transport and issues of sleep and behaviour (as inappropriate transport can affect these).



Questions about the child's behaviour

Q5. Does your child with a disability or additional need display behaviours that you find difficult to cope with? (n=113)

Response	%	Number responding
Often	54%	61
Sometimes	33%	37
Rarely	12%	13
Never	2%	2

All respondents (113) answered this question, with 54% saying their child **Often** displays behaviours they find difficult to cope with, and 33% saying **Sometimes**. In total **87%** of respondents said their child **Often** or **Sometimes** displayed these behaviours, and **13%** said their child **Seldom** or **Never** displayed these behaviours. Those who answered Often or Sometimes were taken to a survey page with questions around behaviour.

This is consistent with what we have heard in the scoping workshops, where behaviour was the most frequently cited issue (27 parent carers) followed by respite (19) and sleep (16). As we will see later on in this report, these issues are interrelated – respite provides a way for families to recharge their batteries (including having a night's sleep) and better deal with the child's behaviour, which often is in response to family stress.

Q6. What is the impact of your child's challenging behaviour on your family? (n=73)

This question was a free text response and each response could include more than 1 impact.

The impact is great as it can seriously restrict what we do or where we go [...] he can display aggressive and or challenging behaviour at any time. This could mean that we cannot take him out which means that our other children are restricted.

Everything revolves around his behaviour daily, often missing events because of melt downs

We can't go out to mainstream places, eat out, we aren't invited anywhere as a family and we can't get a babysitter to go out as a couple

We have no family life. We don't do anything as a family. At home we lead separate lives.

The second most common impact mentioned was around mental health, mentioned by 33% (24) respondents.

Anxiety. Worry. Upset. Depression. Isolation.

I have been hospitalised. I walk on eggshells. I have no freedom.

Can't live a normal life, have to consider impact of everything. Choose not to do a lot of things in case it causes trouble. On edge most of time and taking medication ourselves.



The most common theme was around the **restrictions to going out and doing daily activities**, including restrictions to family life, mentioned by 48% (35) respondents. The third most common impact mentioned was on siblings, mentioned by 21% (15) respondents and the fourth most common impact was around family or relationship conflict, mentioned by 14% (10) respondents.

Other impacts mentioned include: injury to family members or to the child themselves; tiredness; impact on sleep; child's safety; inability to get childcare; impact on child's education; impact on parent's job; time taken to deal with issues; relationship between parent carers and child.

Q7. Have you received any support with your child's behaviour? Please tell us what it was and if it was useful. (n=71)

The most common response to this question was "No", i.e. the parent had not received any support with their child's behaviour. 37% (26) of respondents said this.

Other respondents mentioned some help or support. Not everyone said whether the support was useful, 18% (13) said the support received wasn't helpful and 14% (10) said the support was helpful (including a few parent carers who cited more than one source of support, some helpful and some less so).

The most frequently cited source of support was CAMHS / therapy, mentioned by 17% (12) respondents; followed by social services mentioned by 10% (7) respondents (in some cases a particular team was mentioned such as the learning disability team). 6% (4) parent carers mentioned receiving some theoretical but not practical support; 6%

Making sure that care is managed between all of my children and that he gets the care he needs.

It has a massive impact. He targets my middle son [...] It is emotionally and physically draining and makes me feel like I am neglecting my other 2 children's needs due to his demanding disability.

Stressful. Causes arguments on how best to deal with it. Sibling witnesses it and is shocked by it.

Lack of sleep for me [...] anxiety for me [...] the other children have all left home as has his father

It has nearly split me and my husband up after being together [...] years, has made my son want to move out,

mentioned support from the school; 6% mentioned a behavioural therapist.

Other sources of support mentioned by one or two parent carers included: CALDS; disability nurse; Families First; OT; EMDR; Contact; Adult mental health services; Early Bird course; Health Visitor; CBT; CBC; Afasic Cymru; Challenging Behaviour Foundation; CNS; parenting class; portage.

With small numbers of responses it is difficult to find a pattern as to which services were most useful, e.g. 3 respondents found social services helpful and 3 found them unhelpful; 2 respondents found CAHMS helpful and 5 unhelpful (a number didn't specify) etc.

What is striking is that more than half of respondents either have had no support, or they've had support that hasn't helped.

Support mentioned across the scoping workshops includes:



- In the Powys scoping workshops parent carers also discussed how little support they'd had around their child's behaviour.
- The "early bird" programme for ASD -mentioned in two focus groups. Parent carers had found this helpful.
- Two parent carers also mentioned having had a behavioural study assessment which identified the problem, but they were given no subsequent practical support.
- One parent had attended the Contact behaviour workshop which they had found useful, especially as this had been part of a series of workshops.
- Other support mentioned includes: Makaton and Cognitive Behavioural Therapy helped one parent; one parent had support with journey planning around toilets; one parent had had behaviour support/nurturing programme from the NHS when their child was younger.

Q8. What support would you like in the future around your child's behaviour? (n=67)

The most frequently cited response was respite, cited by 19% (13) parent carers, and 13% (9) parent carers want to find suitable activities for their child. This suggests that a number of respondents are no longer seeking strategies for the behaviour itself, but ways to mitigate the impact that the behaviour is having on the family. We don't know if this is because they've already sought and received the support that was available, or whether they have not received or have given up on finding support.

I would like a break to recharge my batteries to deal with my child's behaviour

Respite is the main issue - either after school on a weekly basis to enable us to take our other children to after school activities or weekend respite so that we can take the other two away somewhere that he would find stressful.

Would like someone to show us how to handle it and prevent him from harming others

10% (7) of respondents simply don't know what they want or need, and 9% (6) would like any help at all. This is not surprising given the high proportion of families who are getting no support at all with their child's behaviour. 7% (5) of parent carers want more of what they're getting or for services to be better, more frequent etc. 6% (4) would like support from the school.

Other responses include support groups and meeting other families in a similar situation; for their child to get individual help rather than the parent attending courses; therapy for the parent; for the parent to be taken seriously by professionals and to receive non-judgemental advice; help with transition; counselling for the parent; advice; more support from SALT (speech and language) as the parent believes the child's behaviour issues are around their inability to express themselves; how to cope; work on anxiety; more training.

In the scoping workshops, possible solutions around behaviour issues include:

- Parent carers would like workshops on behaviour, with one parent suggesting a rolling programme of workshops as one is not enough.



- Parent carers also mention the benefit of getting involved with support groups for support and advice, and how important it is to meet other families.
- Families would also like family fun events to get the whole family out of the house and so that all their children had opportunities to interact with other people.
- Families wanted support during Summer holidays and half terms was also discussed.
- Families wanted face to face support in the home; an advice line; an advocate with the school (if behaviour problems take place at school); and bereavement support that is appropriate for a disabled child. i.e. one family had a child who's behaviour was exacerbated by recent bereavements.

Questions around parent carers' information needs and gaps

Q9. Do you feel well informed about the following (n=84):

This questions asks about how well-informed parent carers feel about different services or aspects of their life with a disabled child.

	Yes, I feel well informed about this topic		Somewhat, but I would like more information and advice		No, I do not feel well informed		N/A This topic is not relevant to me		Total
	%	number	%	number	%	number	%	number	
Services in your area to support you and your family	12%	10	39%	33	49%	41	0%	0	84
Childcare for your child	9%	7	15%	12	56%	45	21%	17	81
Your child's education	37%	31	35%	29	23%	19	6%	5	84
Your family finances (including your options around benefits, tax credits etc)	23%	19	42%	35	33%	28	2%	2	84
Coping with your child's behaviour	15%	13	38%	32	40%	34	6%	5	84
Helping your child to sleep	22%	18	35%	29	30%	25	13%	11	83
Transition to adulthood	2%	2	15%	13	60%	50	23%	19	84
Social care and direct payments	6%	5	26%	22	55%	46	13%	11	84
Short breaks / respite	7%	6	17%	14	58%	49	18%	15	84
Legal issues	2%	2	17%	14	62%	51	18%	15	82
Healthcare for your child	18%	15	42%	35	33%	28	7%	6	84
Mental health and wellbeing for you and your family	7%	6	23%	19	64%	54	6%	5	84
Meeting other parent carers and families	23%	19	39%	32	33%	27	5%	4	82



When we look at the issues or services above, over half of the respondents said they did not feel well informed. If we add those who feel somewhat informed, but would like more information and advice, the topics that come up most often are:

- Services in your area to support you and your family – 88% (74)
- Mental health and wellbeing for you and your family – 87% (73)
- Social care and direct payments – 81% (68)
- Legal issues – 79% (65)
- Coping with your child's behaviour (79%, 66)
- The following services were next on the least, all with 75% feeling not informed or somewhat informed: transition to adulthood; family finances; healthcare for your child; and short breaks/respite.

There is quite a lot of overlap between the two lists with mental health and wellbeing; legal issues; social care and direct payments; short breaks/respite; and transition to adulthood coming up on both lists.

The services where the highest proportion of parent carers feel well-informed (though for each of these, the proportion of those feeling well informed is still lower than the proportion who would like more information) are:

- Your child's education – 37% (31) – but see Q.11
- Your family finances (including your options around benefits, tax credits etc) and Meeting other parent carers and families – jointly at 23% (19)
- Helping your child to sleep – 22% (18)
- Healthcare for your child – 18% (15)
- Coping with your child's behaviour – 15% (13)

The two services where the highest proportion of parent carers said the services were not relevant to them were transition to adulthood – 23% (19), and childcare for your child – 21% (17). This makes sense because these services are age-specific and therefore may not be relevant to all parent carers.

For each of the services above, we asked parent carers **Please tell us if you already receive support with this, and if so from whom.** The purpose of this is for us to understand which services are already being provided, so that (a) we don't duplicate services that others are providing, and (b) we know where to signpost parent carers if a good service is available.

Services in your area to support you and your family- This was the most general category of information and 23 people listed services.

- 5 people mentioned social workers or the council, but not always in a favourable light.
- 2 mentioned National Autistic Society (which has local branches).
- 2 mentioned Tim Plant Anabl, which is the disabled children's team for Ceredigion.
- Other services mentioned include: Family centre Llanrwst; CAMHS; Adult mental health; condition-specific charity (visually impaired); Credu; Action for Children; Hope House Hospice; Derwen; Diverse Cymru; SNAP Cymru; Magic Monmouthshire; ILS; Mencap; SAFAN.



Childcare for your child – 13 people wrote a free text response to this question.

- 6 of these said they were not receiving any services, and a number of these said there was no childcare for the type of needs their child had (or at least no free childcare): *there is no childcare in existence for my child.*
- Two mentioned respite, one saying it had been denied and one saying it was very sparse.
- One respondent mentioned childcare given by grandparents..
- Other organisations mentioned are Afasic on kin; Conwy Monkeys; and Your Space (but not free and restricted).

Your child's education – 21 wrote a free text response to this question.

- 7 mentioned SNAP Cymru, however more than one expressed concerns about cuts to this organisation and them being hard to reach: *Snap Cymru are hard to reach due to cuts*
- 6 mentioned their child's school, special school, college or learning support
- 4 mentioned the local authority including the autism team, council key worker, Tim Plant Anabl (disabled children's team for Ceredigion)
- Others mentioned: private charity, local groups, independent advocacy service (not free), Magic Monmouthshire.

Your family finances (including your options around benefits, tax credits etc)- 12 wrote a free text response to this question.

- 2 mentioned they got information online
- One mentioned information from friends.
- Other organisations mentioned include: Credu, Diverse Cymru, CAB, Tim Plant Anabl (disabled children's team for Ceredigion)

Coping with your child's behaviour – 8 wrote a free text response to this question.

- Two mentioned other parent carers or support groups
- 4 mentioned NHS services including CAMHS, therapy, adult mental health;
- Other organisations mentioned include: Adoption UK (delivers course, but not free); charities; school; CBF; Tim Plant Anabl (disabled children's team for Ceredigion).

Helping your child to sleep – 12 wrote a free text response to this question.

- 5 mentioned health services or medication, in particular a few mentioned receiving melatonin from their Paediatrician.
- Two said they got no support.
- Other organisations mentioned include: private OT; specialist on child's condition based in London; Cerebra; CTLD.

Transition to adulthood- 7 wrote a free text response to this question.

- Organisations mentioned include Paediatrician; School; and council team (CTLD; Tim Plant Anabl).
- A couple stated how stressful transition was:

We've just gone through transition and it's so stressful, now we have to wait 18 months for respite



Social care and direct payments – 8 wrote a free text response to this question.

- 4 mentioned social workers or the DP office, but not all of these had been successful.

Short breaks / respite – 7 wrote a free text response to this question.

- 2 mention that they are not eligible
- Organisations mentioned include Tim Plant Anabl (disabled children's team for Ceredigion) arranging the service via DASH; Family Fund; and Family Placement Service.

Legal issues – 3 wrote a free text response to this question

- Organisations mentioned include Mencap, Cerebra and an Autism Group.

Healthcare for your child – 8 wrote a free text response to this question

- These responses list health professionals such as paediatricians, other paediatric specialists, dentist, CAMHS and other mental health services, health visitors.

Mental health and wellbeing for you and your family – 9 wrote a free text response to this question

- A number of responses stated the issues the family is facing with mental health.
- Services mentioned include CAMHS (including one respondent who said CAMHS repeatedly declined referrals), adult mental health, psychologist, and GP.

Meeting other parent carers and families – 12 wrote a free text response to this question

- 4 mention local support group (3 of these are autism support groups including local NAS branch)
- 2 mention they do not have time to go to meetings.
- Other organisations mentioned include: Adoption UK; Creative Hands (Cardiff Deaf Club); Magic Monmouthshire; Mencap Coffee Morning; SAFAN.

This was quite a long question and some of the categories of services had few free text responses. We don't know if this is because the services are not available, or because the respondent did not have time to write down all the services they access. Ideally the analysis of the data would be at a local level i.e. what services are available in a particular area. However, although we had responses from almost every local authority in Wales, the sample size for each area is too small to give us a true picture of service provision and gaps by area.

Q10. How and where would you prefer to receive advice and information on the above topics? Please tick all that apply. (n=84)

Answer Choices	%	number
Workshops	73%	61
Telephone advice	33%	28
Written / online guides	73%	61
Online workshops / webinars	49%	41



Most respondents (73%) said they wanted information via workshops and/or written/online guides (73%). Just under half wanted online workshops or webinars (*So I could watch in my own time. Late evening*) and about a third wanted telephone advice.

In the free text comments, 4 parent carers said they wanted information by email and 3 parent carers said they had issues accessing services such as workshops.

*not able to get to workshops due to work commitments and childcare issues outside these
Needs to be day time term only*

Two said that they wanted to meet parent carers in the same boat / get information via support groups.

Two said that they wanted practical help rather than information:

Although I feel well informed on the services what I have discovered is that despite knowing what is out there, there is nothing that seems to be making a difference or helping my son [...] So I am well informed but still struggling.

Other routes of getting information mentioned by parent carers include at hospital; at school; via text; via Facebook.

In the scoping workshops, the following routes of accessing information and support were requested:

- Workshops
- School coffee mornings (including with activities or guest speakers)
- Family fun events (including for siblings) and mainstream social activities with support for families
- Support groups
- Advocate or key worker
- Telephone or email advice
- Written guides
- Online workshops
- One parent carer mentioned technology tools, for instance to help write DLA (giving the example of an app that asks questions at set times a day to help populate forms)

Questions about education provision

Q11. Are you aware of the new education law for children in Wales (Additional Learning Needs and Education Tribunal (Wales) Bill)? (n=86)

70% (60) said that they were not aware of the new education law.

30% (26) said that they were aware of the new education law. These were taken to a page with additional questions on the new education law.



This lack of awareness was confirmed by the scoping workshops, where 32 out of the 35 parent carers we spoke to were not aware of the ALN reform.

Q12. Do you have any concerns about the new education law? (n=21)

As only 30% of parent carers were aware of the new education law, there were not many responses to the questions around the new education law.

Even among the 21 who did answer the question on whether they had any concerns about the new education law, 38% (8) did not know. 24% (5) did not have any concerns.

14% (3) felt that the new law was unworkable:

Can't see how it will happen as statement process already takes ages. There isn't the staff to do more for lower need

10% (2) were worried about losing services for their child:

I have some concerns about how this service is going to be provided as it is difficult at present to get Social, Health and Education to work together for any support. I also worry about losing the 1-1 support my son is currently getting as this is very much valued and needed.

I don't know enough about it to be certain but I am concerned at removal of statutory requirements. I welcome the broader remit but worry about how this will affect the profoundly disabled.

Other concerns include: the school saying they will need to wait for the new legislation before getting a statement; not worried if the law is followed; concerns about the statement process; concerns about parent carers having little power; concerns Post 19.

Q13. What support, if any, will you need during the transition to the new legislation, and how would you like to receive it? (n=15)

27% (4) did not know what support they needed. 20% (3) wanted workshops.

13% (2) wanted information and 13% (2) wanted to know how it would affect them.

Additionally parent carers wanted better understanding, leaflets, and advice from school and council disability team.

In the scoping workshops, once parent carers were made aware of the ALN reforms, they wished for more information about this including workshops, online workshops or guides.



Q14. Have you ever called a helpline or used an independent agency for support with education issues? If so who, and what was the outcome? (n=22)

59% (13) mention SNAP Cymru, of these 3 found it useful or partly useful; 2 did not find it useful; the others did not specify.

SNAP. Useful advice but even with tribunals etc... getting educational establishments to adhere to the recommendations is usually unworkable.

27% (6) said they had not contacted a helpline or agency for support with education issues.

I waited weeks for start date for son, school kept saying it was transport, transport were blaming school. Issue was member of school staff being released to be taxi escort. One call to Sally Holland [Children's Commissioner] sorted it out, she's fantastic.

Other organisations mentioned include: British Dyslexia Association; Contact; private advocacy service (Jenny Archer Advocacy); and the Children's Commissioner for Wales.

Questions about needs at different ages/stages

Q15. Thinking back to your own experiences, what do you think are the needs of families whose child has recently been diagnosed with a disability or additional need? (n=71)

This was a free text question where parent carers were asked to think about the needs of newly diagnosed families.

The most commonly cited need was to **meet other families** like themselves, for instance via support groups, mentioned by 32% (23) respondents.

Need to be invited to the nearest support group around them so they learn that they're not on the own because this can take time to realise it's not all doom and gloom

To talk to other parent carers who are 5 years ahead of their child so they can get insight into the reality of system failures and make an informed decision.

Back when our eldest was diagnosed I wanted more support from parent carers the same age as myself. I went to support groups and a lot of parent carers were there with older children with additional needs. I didn't find it much help as my child had just been diagnosed I think there should be a group for newly diagnosed children.

To be in close and regular contact with a number of families with a child with the same diagnosis. To have direct, regular contact.



The second most frequently cited need was “**support**” (mentioned by 31% - 22 respondents), where the respondent hasn’t specified the particular type of support, or means emotional support/ a listening ear.

Support and advice

As much help as they need

Support, it’s quite a scary upsetting time, and you feel alone.

18% (13) respondents mentioned **support specifically around diagnosis** – both getting a diagnosis, and support immediately after diagnosis.

[...] The doctor told me he may never walk or talk, there was no explanation why. I was just left to leave and get the bus home. I feel there should have been some sort of support at the beginning as I had no idea what was going on. There needs to be more support for the children who don’t get any diagnoses also as 5 years on I still have no answers and still struggle to find help.

Fighting to get a diagnosis from the age of 2 and my son is now 14 and just accessing the ASD & ADHD Pathway.

They need clarity re diagnosis and likely impact and support to come to terms with diagnosis

14% (10) respondents say newly diagnosed families need **information and signposting on services available**.

Proper information in an easy to read format with all support groups, benefits, local activities etc

Knowing what support and groups are available locally

11% (8) parent carers say newly diagnosed families need **information** (without necessarily specifying what); 7% (5) say they need information/support on **finances**; 7% (5) say **workshops**; 6% (4) say **counselling**; 6% (4) say better support from professionals incl. keyworker; 6% (4) say advice; 4% (3) say support on education. Other responses include respite; help with paperwork; housing support; positivity; information on service eligibility; independent advice; support with child’s behaviour; activities for child; legal help; help to plan ahead.



Information on the condition and suitable support groups (including SWAN UK or Unique). Information regarding financial support and other local support. Counselling for parent carers if necessary as often a diagnosis can be similar to bereavement when the life parent carers had planned for the child will be different.

support group for parent carers. specific advice as to where parent carers can access services for their child with help to do so - maybe a buddy system with another parent who has a child with the same disability who they can phone say once a week and let off steam.

Post diagnostic support from the service that gave the diagnosis. Sign posting to all local services

Workshops to help the parent carers understand how they can help their child and get support from other parent carers / meet other families. There are not enough workshop currently, our son was diagnosed in May 2017 and we have still not been able to access a workshop

Most comments specified more than one type of need for families of newly diagnosed children.

Support overall i.e. behaviour, education, legal aspects, respite etc. Workshops would work well but they need to be able to be easy to attend, so nearby with childcare available at a convenient time for parent carers to attend.

Parent Carers attending the scoping workshops, also highlighted the importance of joining a support group and speaking to other parent carers. One parent said:

Best friends were sympathetic but never understood. These girls [from the hospital support group] understand [...] forge friendships for life [...] Friends drop you – but here there is no judgement – we have children with different conditions but the same issues – we support each other.

Parent carers mentioned workshops such as early bird, Credu carers, and Contact's early years workshops. Several parent carers had had support with applying for DLA through these programmes, and this was also very useful to them as it reduced the pressures in other areas of their life:

Since this I now have DLA, and manage my meetings really well. I've reduced my working hours by one day a week for respite, but mostly to be able to manage meetings – my employer is very flexible and understanding. I've kept in touch with other group members.

Parent carers would suggest to parent carers of newly diagnosed children to take whatever support is offered (e.g. if they are offered a support plan, respite). Getting a social worker or a health/portage worker was mentioned as useful. Parent carers do feel like they are fighting for everything, and they suggest writing everything down, and getting responses in writing from professionals.



One parent said that once they got their diagnosis things got better, but they would have needed support before the diagnosis as they felt on their own and had little support.

Another parent said that her older disabled child provided support to her younger one, helping them understand their own feelings and behaviour.

Q16. And what are the family's needs when the child or young person is a little older? (n=65)

The most common response to this question was "support" (17% or 15 responses), which was often mentioned together with other needs rather than on its own. Some respondents specified that more support is needed when the child is older. Also in some cases the support sought was support for the young person rather than for the parent.

to be able to talk privately about challenges and not feel judged

This increase tenfold when they get older and with a lot less help all round this may mean one parent having to give up work to look after them, putting yet more stain on the family.

To ensure that the right support is put in place. Knowing where to go/who to contact for help/advice.

11% (10) respondents thought parent carers of older children needed support around transitions (in some cases this was mentioned in conjunction with another service, for instance education), and 11% (10) respondents thought help was needed in the process of the young person gaining more independence, including supported living and work advice.

trying to be independent when others don't understand their needs

Advice, support and transition

support for the child/young person, help to support their independence at a suitable level, transition to adulthood and services, financial support, guardianship etc.

transition help, education, finance and work advice.

*Support with working out how to support young person into adulthood in the most positive way for the family
e.g. supported living*

A lot more since they now have choices

Help enabling transition into secondary school, then with independent living and then having a job.



10% (9) say that families of older children need help with education.

Knowing what they can claim. How they can access further education. About assisted living.

[...] transition help, education, finance and work advice.

5% (4) respondents say families need help with finances.

*He is going to get bigger and stronger and the meltdowns and aggression are going to be harder to deal with.
Any advice on how to cope with this will be needed*

*very challenging as the young person gets older - what is acceptable in a small child's unusual behaviour become
much more noticeable as they get older and bigger. Respite.*

5% (4) respondents say families need help with the young person's behaviour, in some cases more so than when the child is younger:

*Lots of support and understanding of ALN from education. Listen to what does and doesn't work for that child so
that they are happier, less triggers The child is happier, teachers are happier which means home life is happier.*

Transition to high school

Other needs mentioned are: support with socialising; going through puberty; advice; meeting other families; support from the community; signposting to services; CAMHS; worry about when parent carers can no longer care for the child (*What happens if parent carers are unable to care? Adult social care is very upsetting to think about*); holidays; bullying; safety; equipment; housing; others understanding needs; physiotherapy; activities; legal advice e.g. guardianship; information.

Transition is scary. It would be useful to have more specific transition support from a relatively early stage.

Q17. Which organisations provide these services in your area? (n=61)

This is a general question and unlike question 9, it is not service specific. Its aim was to capture any other organisations and services in Wales that we were not aware of.

Nearly half of respondents (48% or 29) said they didn't know what services were available to meet the needs they had identified for newly diagnosed families or families whose children are older: this may be because if they have identified these as needs, it's because they're needs that have not been met.



Other services mentioned include many of those which have been mentioned in Q9, plus a few new ones. These include: Derwen; Social services/LA; Snap Cymru; NHS; CAMHS; Tim Plant Anabl (disabled children's team for Ceredigion); Families First; Team Around the Family; Safan; NDCS AUK; Autism Group; Barnardos; Action for Children; DSA21Plus; Challenging Behaviour Support Group (CBS group); Building Bridges; NAS; Sparkle; Newcis; CALDS; Careers Wales; School; Joining the dots; Mencap; Family centre; Young carers YMCA; Family information services; Gogarth. Some mention services like Afasic and Contact but say they are no longer providing services in Wales or in their area. One respondent says there are too many signposting services and not enough other services.

Like Question 9, ideally the analysis of the data would be at a local level i.e. what services are available in a particular area. However, although we had responses from almost every local authority in Wales, the sample size for each area is too small to give us a true picture of service provision and gaps by area. For example one respondent said service provision is poor in Powys, and another respondent said service provision is very good in Ceredigion (*I'm very grateful that things are so seamless in Ceredigion, with social services, school, and NHS working together so well*), however this may be due to their individual experience.

Q18. What are the gaps in services for families with disabled children in your area? (n=58)

The most common response is "Don't Know" (17% or 10 respondents). Other commonly mentioned gaps are respite and activities (each mentioned by 10% of respondents); services for older children (mentioned by 9%); support for education and holidays (mentioned by 7%); issues around travel for those in more remote areas (mentioned by 5%); issues around services for particular disabilities mentioned by 5%

I think that there is a lot of support for those that have severe disabilities but not so much for those that don't have physical disabilities or are seen as coping much better in different situations.

mental health support (mentioned by 5%); signposting to available services (3%) (in this case the parent felt there is a *Lack of communication rather than gaps in services. Although a lack of respite/short break provision*); financial support (3%); issues around social services provision and quality of service (3%); lack of funding for services (3%); poor communications from services to the family (3%). Other gaps mentioned include: services outside school hours; direct payments; emotional support; issues around length of waiting lists; SALT; workshops; childcare; support for single parent families; behaviour support; someone to talk to; assessments; diagnosis support; NHS; independent advice; local groups.



Conclusions

The evidence we were able to gather thanks to Awards for All funding enables us to draw conclusions on the information needs of families with disabled children in Wales.

Both the focus groups and the survey highlight **behaviour** and **respite** as key challenges for parent carers (with **sleep** a related issue). In this case it seems that gaps in services (in particular around respite) go hand-in-hand with information gaps (in particular, on handling challenging behaviour and sleep issues).

The other key finding of this scoping exercise is the lack of knowledge about the forthcoming education reforms (ALN Bill) which is anticipated to come into effect at the earliest in September 2019. Most parent carers were not aware of this change. The Wales code of practice for this new process is being written now and when the statementing process changes parent carers will need to know what this means for them.

Finances were not in the top issues mentioned, which was surprising as typically this is the most frequent topic of enquiry for families who get in touch with Contact. This might be because the parent carers surveyed were relatively better off, or because they were already informed about the financial support they can receive. However, parent carers do recommend that families of newly diagnosed children do get assistance with finances. Moreover, it is clear from the comments that assistance with finances, for those who'd had it, had helped with other aspects of life:

Contact Early Years workshops June 2017. These made all the difference to me. I almost didn't come. Since this I now have DLA, and manage my meetings really well. I've reduced my working hours by one day a week for respite.

And we can also see from the survey responses that finances can affect health and well-being; and that issues around education and care affect the parent carers' ability to work and therefore finances.

We were not expecting to find that parent carers recognised their own and their families' mental health issues. In one of the focus groups parent carers expressed how they feel like they are fighting for everything, and this came out in some of the free text survey comments as well. Something that was perhaps less surprising was the keen awareness (among survey respondents and workshop attendees) of how helpful support from other parent carers can be, and all parent carers recommend access to support groups for themselves and parent carers of newly diagnosed children.

Workshops and written guides are the most popular ways of receiving information. The combination of the social/support element of workshops/information sessions is recognised by parent carers, and in the scoping workshops parent carers also mentioned getting information and support via coffee mornings at school and family events.



Moving forward

We intend to use the findings of this scoping project to create the delivery model of an ambitious sustainable project that will address the issues parents face across Wales, and provide the level and depth of local support to families that they are indicating is essential. This project will give parents confidence and combat isolation and increase sustainability through various measures including by supporting and assisting independent Parent Support groups, and filling the gaps of information and knowledge that they need to support and advocate for their children. ie a staggering 48% of parents did not know what services were available to them. And 78% were not aware of the ALN reform which is expected to occur in 2019.

The Awards for All “walking with us” grant has enabled us to collect powerful evidence of the need and requirements of Parent-carers across Wales that we will use in our applications for funding for this future project. It will be translated into Welsh and it will be shared through our website.



Thank you

With thanks to all the Parent Carers who took part in this scoping exercise.