



Draft ALN & Education Tribunal (Wales) Bill Parent Consultation Response

About Us

SNAP Cymru is a registered charity which has successfully empowered families in Wales over 25 years, enabling them to have their 'voices heard' within the area of special educational needs and disabilities. We have supported families to influence policy and practice in the planning and delivery of services both locally and nationally and therefore have a wealth of experience gathered over time and under changing legislation. We provide a Disagreement Resolution Service, Specialist Advocacy for Young people an accessible website and hold the Community Legal Services – Specialist Quality Mark for Education Advice in recognition of our legal advice service for families.

SNAP Cymru is proud to be the leading Parent Partnership Service in Wales, providing accurate and impartial information, advice and support to families, parents, carers, children and young people in twenty Unitary Authorities. Our Parent Partnership Service ensures that parents are fully informed of their legal rights and responsibilities as well as the differences in local variations of policy and practices. Our aim is to establish, develop and maintain the trust and confidence of both families and professionals in order to effectively deliver a professional service.

This relationship provides us with a unique opportunity to support children young people and their families, to listen to their views and to support the development of services and policies for Children and young people with Special Educational Needs. We look forward to continuing to maintain and develop the professional standard of PPS staff to accommodate any new legislative changes.

We recognise that in order for parents to feel confident and involved in the proposed framework they will need accurate and impartial information, advice and support that is in line with any proposed legislative changes SNAP Cymru will continue to see this as an essential element of our charitable aims.

SNAP Cymru held a series of consultation events throughout November and December 2015 which were designed to support children, young people and parents make an informed contribution to the WG consultation on the Draft ALN & Education Tribunal (Wales) Bill. The events were advertised to parents and professionals through SNAP Cymru's website (www.snapcymru.org); referral database and partner organisations from November 2015 onwards. **(12,839 individuals** viewed our ALN consultation information pages on the SNAP Cymru face book and website)

167 people attended 15 events throughout Wales

182 people completed the online survey

349 people in total responded

Whilst initially developed for children and families, several schools and third sector professionals requested to be included. SNAP Cymru has also been contacted by an additional 10 groups wanting to hold a consultation in their area. (A full description of the participant groups are attached.)

Each of the events followed the same format:

A facilitator gave an informed presentation of each section of the proposals, followed by discussion and responses in small group which was recorded directly onto flip charts/laptops. Participants were shown several examples of proposed IDP's gathered from LA's across Wales, and completed several person centred activities to have a flavour of the participatory nature of the proposed process. A bilingual online survey was distributed via Mail chimp to families who are/were beneficiaries of our casework service during 2014/15.

Four Welsh language consultations were facilitated with children and young people with ALN in Ysgol Y Moelwyn & Ysgol Brynrefail and with parents and pupils in Denbighshire and Conwy. This report contains the raw, aggregated responses.

(Attendance records, including individual details are available for each event on request as is original source material.)

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Consultations held:

Establishment/Group	Attendees	Date(s)	County
Challenging Behaviour Group & RCT Asperger's Group	32 parents 15 parents	05/11/15 3/12/15	RCT RCT
NPT Professionals	5 professionals	16/11/15	NPT
Ysgol Y Moelwyn Secondary & Ysgol Brynrefail Secondary	10 young people (5 from each school)	16/11/15	Gwynedd
Friends of the Young Disabled (FOYD) Diversity Parents Group	11 parents, 2 professionals	16/11/15	Swansea
Ceredigion Parents & Carers Forum	9 parents	17/11/15	Ceredigion
Stepping Stones Parents Group	7 parents	20/11/15	Swansea
PAVS/Action For Children/NAS/Parent	6 professionals; 2 parent	23/11/15	Pembrokeshire
Ysgol Bod Alaw Primary	5 parents	25/11/15	Conwy
Jigsaw Parents Group Swansea	7 parents	27/11/15	Swansea
Pentrebane Primary School with ASD unit	6 parents	2/12/15	Cardiff
Home Educators	6 parents	7/12/15	Swansea
Roath Park Primary School	6 parents: 3 professionals 1 child	7/12/15	Cardiff
Ysgol Glan Clwyd Secondary	6 parents	08/12/15	Denbighshire
Cardiff and Vale NAS Parent Support Group & SNAP Parents	5 parents 2 professionals	8/12/15	Cardiff
SNAP Cymru	21 professionals	15/12/15	All Wales
SNAP Cymru Beneficiaries	182 responses	16/11/12- 4/12/15	All Wales

County coverage of consultees

Blaenau Gwent	0.62%	2
Bridgend	3.10%	10
Caerphilly	4.02%	13
Cardiff	17.65%	57
Carmarthenshire	2.79%	9
Ceredigion	3.41%	11
Conwy	2.79%	9
Denbighshire	3.72%	12
Flintshire	0.31%	1
Gwynedd	7.12%	24
Merthyr Tydfil	1.86%	6
Monmouthshire	2.79%	9
Neath Port Talbot	3.72%	12
Newport	3.10%	10
Pembrokeshire	4.64%	15
Powys	1.24%	4
Rhondda Cynon Taff	13.93%	45
Swansea	18.58%	60
Torfaen	0.62%	2
Vale of Glamorgan	2.79%	9
Wrexham	0.62%	2
Ynys Mon	0.93	4

Individual Development Plans

Question 1

What do you think is the best way to produce an IDP so it can easily be transferred between schools and/or counties?

5% With no standard format

76% With a standard format that is consistent across Wales

17% A different format for early years (pre-school)

1% No IDP format for early years but have a person centred play plan

13% Through other means

- Every IDP should look and be the same so everyone is on the same page.
- All authorities need to have the same structure.
- If they are all uniform, it will be parent friendly and be easier to follow child/young person on their pathway.
- Where will out of date information on plan be stored and for how long?
- Security of information is important and needs to relate to parental permission and clear determination of whom or what falls within "need to know". Similarly, any alteration of data needs to be communicated to / agreed by parents. A full history needs to be available as secure archive, for possible future reference.
- With a standard format that is used across Wales and the child / young person is supported one way, i.e. it is easier for 20 people to learn one way, rather than the child individual, learning 20 ways.

- I can't see a teacher having the time to complete these IDP's, as they already struggle enough with IEP's.

- There are 23% of children with IEPs and 2/3% with statements how will ALENCos complete them all
- A standard document that stands out would be preferable. It's not so much the process, but it is important that the information is looked at and included.
- I think a one page profile would be best. It would be good for supply teachers.
- The IDP should go with them from placement to placement
- It has to be a standard template for every child that is the same format throughout Wales.
- The best way would be to have an Action Plan which clearly sets out the next actions to be followed.

- Formal plans for both Early Years and older- but with a distinguished difference as needs could be different.
- Plans need to be standard for consistency across Wales, otherwise difficulties may arise and people move counties.
- Nodwyd nifer o'r bobl ifanc nad oeddent yn hollol ymwybodol o'r system cefnogaeth sydd yn ei le ar hyn o bryd, gyda rhai ddim yn ymwybodol bod ganddynt CAU. Ac felly cafwyd trafferth medru cymharu ond mynegwyd barn ar enghraifft o CDU a chafodd ei chyflwyno iddynt.
- Cynlluniau Datblygu Unigol: Cryfderau
- Maent yn gefnogol i fod yn ganolog i'r broses o'u llunio ac adolygu a chael perchnogaeth ohonynt.
- Maent yn ffafrio adolygiadau tymhorol ac na ddylid eu cynnal heb hwynt yn bresennol.
- Maent yn cytuno bod llun ohonynt ar y dudalen flaen i'w groesawu ar yr amod ei fod yn cael ei ddiweddarau'n rheolaidd neu hefo'r opsiwn o ddewis cartŵn, darlun ei hunain neu lun o rywbeth pwysig iddynt.
- Maent yn deall yr angen i gynnwys gwybodaeth ynghylch yr hyn sy'n bwysig iddynt a'r hyn sy'n bwysig ar eu cyfer ynghyd â'r hyn sy'n gweithio a ddim yn gweithio iddynt.
- Maent yn gwerthfawrogi'r angen, os yn briodol, i osod targed mewn perthynas â gostwng lefelau cymorth er mwyn hyrwyddo annibyniaeth.
- Maent o'r farn y dylai pob disgybl yn yr ysgol gael cynllun o'r fath oherwydd nad ydynt eisiau teimlo'n wahanol.

Cynlluniau Datblygu Unigol: Gwendidau

- Maent yn anhapus na fydd y drefn ddiwygiedig yn dechrau'n syth.
- Mae ganddynt bryder gwirioneddol ynghylch cynlluniau electronaidd o safbwynt diogelwch a'r risg o wybodaeth sensitif yn cael ei hacio. Gwell fyddai ganddynt gyfundrefn bapur.
- O safbwynt y proffil ohonynt, maent o'r farn y gall fod yn rhy bersonol a chyhoeddus. Maent o'r farn mai dim ond gwybodaeth allweddol bwysig ddylid ei gynnwys. Nid ydynt am i bawb wybod popeth amdanynt ac maent eisiau'r hawl i benderfynu pa wybodaeth i'w rannau a chyda phwy.
- Nid ydynt yn fodlon i eraill ddiwygio'r cynllun heb eu caniatâd.
- Maent yn credu y bydd arnynt angen arweiniad ac amser i ddeall y drefn newydd.
- The earlier a standard format is introduced to parents, the easier the system will become.
- There should be no deviation in early years 0-25, should mean just that.

- The IDP still needs to contain a detailed background of child's needs, diagnosis and provision.
- I think a different format for primary and secondary school would be more efficient and these should be consistent across Wales.
- A format that is recognisant across Wales, England, Scotland and Ireland!
- A standard format that is consistent across Wales, otherwise there would be no consistency across schools, with some providing very little information.
- Different design for pre, primary, secondary and further, higher education. Degree level and suitable trained specific professional's inc. teachers, CAMHS and Ed psychology reports and assessments these have to be individual any format will however well intend put kids in to set plans that will not be the best they can have just the easiest for the school
- I agree there should be a standard format consistent across wales, there should be a different format for Pre-school and there should be a personal centred play plan for early years.
- The approach would need to be individualised to take into account all different needs, including medical. Often the assessments are designed for children with disabilities and do not take into account medical needs, which can be very complex and individual, such as type 1 diabetes.
- Standard format, but it would be helpful if all children with additional needs had one regardless of level of functioning or cognitive ability e.g. autism
- I think there needs to be a standard format as a base to work from but with some flexibility. The overall goals are usually very broad and there should be sections to give examples on how to meet them.
- With space for PCP
- It needs to be different and individual to meet the ages and different problems or circumstances or needs if the individual. A lot of children don't fit into 'a box' so would therefore require an individual format.
- Every child (and their needs), should be treated as an individual, however the document needs to be standard
- Never mind just Wales, it needs to be consistent throughout England and Wales, all education providers need to be on the same page
- This also needs to be consistent in other education sectors in England and Wales also, some SEN children have to study away from their homes. in some cases these colleges are not always registered with FE status, and this can cause enormous problems with funding out of catchment.
- With a basic standard format - but - with the necessary individual flexibility so that it suits the individual person & their needs, and not the provider. It must be 'updateable' but with the minimum of fuss and formal re-assessments.

- Produced by the SENCO of the nursery and discussed with the parents fully to ensure it covers all areas of concern, prior to being discussed with the school, EP etc.
- There appears to be inconsistencies across counties that can be confusing for families and professionals alike. There needs to be a standard format across the board including pre-school and early years, the most important time to identify needs and cause less stress and upset to all young people who suffer unnecessarily due to lack of structure and information
- I think all reports should follow the same format, so they are uniform to a certain degree but with room to be adapted to an individual.
- There should be an element of standardisation, however the plans should be flexible enough to ensure that the plans represented the needs to the child in a truly person centred approach.
- I do not think the IDP is the best format or way forward for the young person. Wales needs to follow the process of an Education and Health Care Plan (EHCP) in line with England. The EHCP's process allows the pupil/young person's whole needs to be cater for with a multidisciplinary approach across all sectors who are providing a service for the young person.
- Everyone is completely unique, as are there difficulties and this must be reflected and understood. However the format should be standard
- It needs to be a flexible document, assessed at regular intervals. All of these children learn differently and at their own pace. It should also have a maximum input from parents and use all of the tools that are found to work with a particular child.
- To clearly identify the child/YP's needs in a uniform manner across Wales and across settings. To clearly set out (with legal protection) how the child/YP's ALN impacts on learning, and specify what support is required, when, and from whom. To set this out in a systematic way ensuring accountability from professionals across services (e.g. health, education and social care), using the person centred approach. For this to be reviewed regularly as a matter of course, and additionally whenever else a review is felt to be needed by any involved parties.
- Needs to be individualized but with a loose structure. Cannot have a standard format because this will impinge on flexibility of provision due to variances between children
- Also need to target different key stages from nursery to college.
- My view is that an IDP needs to be issued in a uniform format and consistently applied across Wales as it would leave a gulf between LA's, which would make the process messy, especially if you transferred from one LA to another. some debate around whether three formats for current three stages might be best
- For a child WHO NEEDS multi-agency input, e.g. with health as well as educational needs, there MUST be a way of working together across their

CURRENTLY very demarcated boundaries in the first place. Then there must be a clear and transparent way of transferring this information and working quickly and efficiently from school to school, as otherwise the health and the education of the child can deteriorate very fast and this also has an emotional backlash too.

IT HAS TO BE TRANSPORTABLE, CLEAR AND TRANSPARENT BUT MOST OF ALL IT WILL NOT WORK UNLESS ALL PARTIES SIGN UP TO FOLLOWING IT OTHERWISE IT IS NOT WORTH THE PAPER IT IS WRITTEN ON!

- Through an assessment by local authority only, not at all through a school ever. Especially on complex needs children should continue to have a statement of special educational needs as many have medical disabilities that a school shouldn't be dictating on. Even children whom are home educated should be allowed to be given all the rights as school children to their right to therapy etc.
- Uniform structure and individual content!
- I cannot stress enough how important it is for IDPs to be quantifiable, detailed, specific and adequate to meet the child's needs. This needs to be clearly stated in the bill.
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- Will an IDP indicate school placement / choosing a school? Because school based, to produce IDP, conflict of interest could give a school more power to remove a child from their school if they don't want them or too expensive to provide them provision.
- How will parents know what their rights are as not in LA's interests to inform them if it will lead to tribunal etc.?
- Who will have IDPs – who decides / overseas school decisions to see if fair?
- Can Health recommend to LA an IDP is written for a child?
- Will EP's become more available for school usage if they no longer have to write lengthy statement reports.
- Would be good if Young Person could have IDP and support in work placed learning and higher education too.
- IDP doesn't look like it will have as much room on the statement to give detailed information about a child

Question 2

What support would you like to see if you are considering whether your child's IDP will meet his/her needs?

15% Help and support from my child's school/college and local authority

73% Help and support from my child's school, college, local authority *and* an independent person

13% Through other means

- Support should be impartial and independent.
- I have a lot of informal support from charities such as Hands Up For Downs and Bobath. I don't think I would have the courage to voice my concerns to "Official" people unless I had had the support.
- An Independent person such as SNAP – I've used them before.
- Independent person advocating for our children is really important. I have used SNAP services in the past and always valued their independent and impartial advice.
- Independent and expert advice at review stage.
- I feel its really important that an independent person who has no affiliation to the school/la should be involved who understands the "condition" the child has and the issues they have and are likely to have in the future
- Multidisciplinary approach. One of my children has a statement, and I'm in the process of applying for my other child. She has receptive and expressive speech and language difficulties as well as ASD so advice from appropriate professionals would be beneficial.
- It is essential that teaching staff understand a child's needs. My son attended a communication disorder unit. I was told by the LSA that 'oh, they're all the same' meaning the children. *No. They're not.*
- Train the teaching staff.
- Help and support from education, health, social care, third sector as appropriate, together with the help of an independent person/advocate if the family requires this (but family should have a RIGHT to this person being involved). Linked to the NICE Guideline on transition from children to adult services which is due to be published imminently
- All of the above answers count, but essentially the parents know what their child needs are fundamentally. The parent should be consulted on what their child needs, and be included in all meetings regarding their child. They should not be excluded from decisions that relate to their child, and should be able to sit in on all meetings and contribute.
- If IDP is to be implemented then it would be good to do one as opposed to just not bothering. E.g. child with autism and epilepsy age 12, still does not have IEP or BHP even though parents have asked several times!
- A lot of parents are unaware of what support they are entitled to and would have difficulties understanding the IDP. I think they should receive support from an Independent person yet be given the information from the school by means of a regular meeting with all parties, including the LEA.

- Possibly the Children's Commissioner should get more involved.
- My experience is that the plans vary depending on who has written them i.e. which teacher in which year group. They are very superficial and don't really address the underlying issues that my child has.
- I've chosen "other" here because schools and LAs have absolutely no expertise, in our experience, in Down's syndrome - we have to deal with an endless train of people who have their own little area but none of them - literally none - specialise in the thing we need them to know about. So, there needs to be someone from an organisation that actually knows about the relevant needs (e.g. schools advisory service of Ups and Downs Southwest). At the moment, various charities or support groups do this on a random basis - if you have the good luck to live in the right area, you get help.
- Help and support from my child's school, college, local authority and an independent person - AND with consultation with the parent who, nine times out of ten, KNOWS their child better than anybody, including 'professionals'.
- Full support from the nursery/school and MCC ALNco, there is a serious lack of EP's and therefore waiting times to be seen are far too long.
- Support in school, home and community - flexible to meet needs.
- It is necessary to have an independent person, I feel, in order to ensure the young people are gaining access to the support and education that fits their needs. All schools are subject to estyn Reports and it is necessary to have independent qualified professionals/educationalists to ensure the process is for the benefit of young people and not according to budgets.
- Some schools don't have adequately trained people adding to goals on IEP's. At my nephew's school a learning mentor said "not singing when it annoys people" is a goal. It is a bit vague for a child on the ASD spectrum. It needs to be specific achievable realistic targets. They also need to read a child's file. A senco said my son is appalling with his scissor skills. I suggested that would be his dyspraxia which was news to her.
- Through independent advisory body
- An independent EP assessment. There should be a voucher for parents to select the EP of their choice and not one employed by the LA. The LA EP will always be more concerned with their employer's budget than the child's actual needs. This would reduce the potential for conflict right at the start of the process.
- Help and support from school/college, local authority, independent groups and above all, must be told what their rights are, what they are entitled to. We never were told (Snap is not to blame here, they helped us loads I'm speaking about other areas of help). The effects have been devastating for us.
- Making sure that all health aspects are taken into consideration as soon as possible.

- Dedicated staff to work with these children. My son's SENCO in primary school was brilliant and put everything possible in place for him. The one in secondary school doesn't seem to be bothered and from my dealings with her, I'm not convinced she understands enough about ASDs. So, school/local authority/independent person and please, please, please - listen to the parents!!
- Multi-disciplinary discussion in the agreement of support provided by medical, SALT OT and other experts to School College and local authority. Holistic support requires holistic input by all specialists involved in agreeing a child's IDP. IDP can be implemented through schools but not planned by schools/LA alone.
- My son has his education delivered at home, we are often out of touch, I would be concerned about receiving relevant training and support for this
- Bydd cyfarfodydd gyda grwpiau o blant ag anghenion tebyg o fudd.
- Credant y byddai cyfarfod briffio ymlaen llaw'n werthfawr.
- Mae rhai eisiau'r cyfle i deipio eu barn yn hytrach na'i gyfleu ar lafar.
- Maent yn dymuno cael y dewis o gefnogaeth Eiriolwr, gyda rhai'n fodlon i'w rhieni gyflawni'r swyddogaeth honno.
- Cytunwyd gyda gwerth trafod gobeithion a bod yn rhan o osod targedau perthnasol, er mwyn lleihau ansicrwydd ac i greu gwell dealltwriaeth o'r gefnogaeth yn ei le neu sydd angen ei gostwng/cynyddu yn dilyn unrhyw gynnydd/dirywiad.
- Trafodwyd eto bod angen dull o fedru mapio allan syniadau er mwyn dewis prif gasgliadau. Ond codwyd pryder na fyddai gan blant ifanc oedran cynradd y ddealltwriaeth a'r gallu i wneud penderfyniadau drostynt eu hunain.

Question 3

Do you agree that the draft Bill would create a robust legal framework for the preparation, maintenance and review of IDP's?

63% Yes

37% No

- If it's all structured the same in each county, then I believe so, but if each IDP is different, then no.
- Draft Bill sounds good, but not enough evidence at present to comment either way.

- The draft Bill is only as good as its implementation and response to scrutiny. There are many complex and difficult cases. I'm not convinced that this Bill will improve matters for them.
- It can only be better than the current process
- It is untested, but interested parties find ways to discover loopholes in systems or find avoidance and evasion routes.
- We need more guarantees. In principal it sounds great.
- Need guarantees!
- It sounds good in principle, but I would want greater detail on guarantees.
- Need greater detail on guarantees that it will work.
- It sounds very aspirational. But I'm really worries about the practical application
- The IDP should be electronic so it can be accessed by everyone and, I as a parent, would know when it's been changed.

- There needs to be a system the same for complex needs that are home educated they require the exact same rights as a school child, this should be made compulsory in law too, as complex needs children are being seriously failed by the current system in place now
- I am concerned being a home educator that there would be a lack of information, support, training and resources with the new bill. Its very reliant on the goodwill of the LA despite there being a mention of those educated otherwise in the proposed bill.

- Yn gyffredinol, credai'r grŵp bod y ddogfennaeth a ryddhawyd hyd yma gan Lywodraeth Cymru'n brin iawn o ran manylion sy'n achosi anawsterau dybryd wrth geisio ymateb.
- Mynegwyd syndod bod diwygio'r ddeddfwriaeth hon wedi cymryd cyhyd a bod gohirio pellach yn yr arfaeth.
- Croesawyd addwewid Llywodraeth Cymru na fyddai i unrhyw blentyn golli'r warchodaeth gyfreithiol a'r ddarpariaeth a gaiff wrth drosglwyddo o'r gyfundrefn gyfredol i'r un newydd ond byddai'r grŵp wedi gwerthfawrogi manylion ac amserlen ynghylch y trosglwyddo.
- Credai'r grŵp y dylid sicrhau bod y gyfundrefn newydd yn sefydlu cysondeb ar draws Cymru er mwyn osgoi'r sefyllfa gyfredol o fynediad at ddarpariaethau, bodolaeth datganiadau a deilliannau'n seiliedig ar god post teulu. Yn benodol, ystyriwyd bod angen meini prawf clir a diamwys ar gyfer penderfynu ai ysgol neu ALL ddylai fod yn gyfrifol am GDU.
- Nodwyd y farn bod y gyfundrefn newydd, i raddau helaeth, yn ymdebygu i'r drefn gyfredol ond yn defnyddio termau gwahanol h.y. CDU ysgol yn cyfateb i weithredu ar y cyfnod ysgol a mwy a ChDU ALL yn cyfateb i ddatganiad.

- Rhagwelwyd, gan mai'r ALL sydd yn y pendraw'n gyfifol am bob CDU, y byddai angen iddynt sefydlu trefniadau monitro cadarn ar draws darparwyr blynyddoedd cynnar, ysgolion a cholegau addysg bellach, a hynny mewn cyfnod o doriadau sylweddol.
 - Mynegwyd y farn mai naif yw cred Llywodraeth Cymru y bydd y cynnydd mewn cyfranogiad a arfaethir gan y drefn newydd yn arwain at lai o wrthdaro, ac y byddai profiad rhieni o orfod brwydro am ddarpariaeth yn parhau. Rhagwelwyd, yn enwedig yng nghyd-destun toriadau mewn cyllidebau ysgolion, y byddai pwysau gan ysgolion a rhieni i sicrhau CDU ALL a'r cyllid canolog ynghlwm â hynny.
 - Credai'r grŵp bod y dyletswyddau a osodir ar Fyrddau Iechyd yn hynod wan ac yn anhebygol o sicrhau bod therapïau hanfodol yn cael eu darparu. Crybwyllwyd yn benodol y cymal "wedi cytuno" a safbwynt cynnwys darpariaethau iechyd mewn CDU. Ymhellach, nodwyd bod peido gosod dyletswyddau statudol clir a chadarn ar Fyrddau Iechyd, a pheidio sicrhau bod Byrddau Iechyd yn atebol i'r Tribiwnlys yn ei furf newydd, yn tansilio bwriad gwrediddiol y diwygiadau i sicrhau cyfundrefn holistaidd sy'n cyfarch anghenion addysgol, iechyd a gofal cymdeithasol plant a phobl ifanc.
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- Don't think that things should change. I'm happy with system as it is – It's taken 12 years to get the support he has now.
 - The system does take too long currently.
 - This IDP process will take longer. There doesn't seem enough time to share all this information with the professionals. Will the IDP be flexible to change
 - Plans are based on what the professionals think about my child. They ask my opinion, but I don't feel that they listen to me. They only see my child for a set time. I am the expert on my own child.
 - The IDP should go with them.
 - Theory is great, but in practice, it's not going to work. They already cut and paste on IEP's. I think they will cherry pick the nice bits out.
 - Professionals will only look at information significant to them. They are not always interested in the full picture. They only show interest in whatever affects their involvement.
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- I hope so.
 - Not the way in which it stands at the moment. Unclear who is taking the lead?
 - I am concerned that the IDP's are not as detailed as the statements or SEN.
 - It is unclear to me who will be responsible for producing the document and what the threshold between school based IDP's and LA IDP's will be?

- Still unclear and undecided on this.
- A legal basis for this work is long overdue. Parents and children should always be allowed and encouraged to be a part of planning and to challenge decisions made by institutions that affect them.
- I can't see how extra support and duties can be put in place with no extra funding.

- Would need legislation to make sure IDP is adhered to.

- My children are home educated- I recently had a PCP review with Swansea LA and completed a OPP- it worked well.

- As a home educator it's sometimes difficult to access services. Our LA has a pathway for DCD and ADHD which involves going through the school based graduated response as a precursor to referrals to CAMHS or OT services. How will this work for home educated children and young people. Much of the document refers to school and FEI's.

- Cannot emphasise enough do not leave support and advice to LA and schools NOT GOOD ENOUGH - Huge personal experience of this for past 4 years
- Cost cutting! Numbers have dropped in England since the reforms
- The focus on schools being largely responsible for deciding what (and if) special measures are in place is ridiculous. Teachers and ALNCOs are not experts. I have yet to forget the ALNCO who pronounced my son as merely being lazy and he could do things if he wanted. My son's statement was turned down and he had a rubbish IEP up until September (change of school) and no IEP in place now. Giving schools more responsibility will just lead to more people in my situation and a lot more frustrated kids.
- Doesn't appear to have the same legal standing as a statement. No distinction between school action, school action plus and statementing equivalents.
- I'm worried about access to expertise, I don't think this proposed system offers more confidence or assurances.
- Anything would be better than the way my child has been dealt with at the moment.
- From what I have seen it will just add layers of difficulty when parents want to challenge the school on what is being provided. From my own experience they are just not qualified enough to cover all the different needs there are

- There is very little information in regards to medical needs for children at school. This care cannot be solely taken over by teachers or assistants. Sometimes a dedicated 1-1 is the only way for that child.
- I'm sure as not too familiar with all the changes, but children with additional needs should be able to access the support they need much quicker
- No the system doesn't work now, so changing it won't fix it
- Very unsure as it's not very easy to decipher. Not sure why health needs are no longer part of it. I'm concerned there won't be the medical input
- I have not read the draft bill, but any changes that could remove Statements, IEP's or ALP's etc is concerning though I do believe a consistent format used across wales would be in the best interest of children with additional needs.
- Hopefully because I have not had the best experience with a School previously and my sons additional learning needs
- It's very vague and it doesn't seem to know exactly what it will look like. I want far more information-the bill is very bare bones
- Not sure as existing legislation is not adhered to and a constant battle
- Only if the rules were adhered to and implemented correctly, these plans need to be specific to the child concerned and the only way it could be robust enough is, if it was routinely checked by an external body or regularly checked by way of email on a termly basis?!
- If all are consistent and there are procedures in place that must be followed - there will be effective results - best support for children with ALN. In my experience, the code of practice is not followed as it should be. Not enough staff, funds, no time, difficult to seek parental advice and involvement.
- As long as it was drafted correctly taking all aspects into account
- I worry that the children's needs is still focused around budgets. I feel it maybe impossible to get all the professional at the same meeting. I am concerned that it will be too fragmented. I am worried about data protection.
- Have little faith in the system as it stands, the whole of education needs a long overdue overhaul (including school admissions and catchment areas).
- It depends how it is implemented and used. My child's learning difficulty is individual as is every child with autism, and strict rigid system is not necessarily the best in our scenario. When my son started nursery I was told once the LEA undertake an assessment you can't reassess for six months. We avoided having our son assessed because of this and have gone with the the school have provided (1hour a day each day). This has been helpful but in the first years of school it would have been good to have more help. My sons needs have changed since he started school and if we had gone with the 6month LEA assessment some of needs would have been missed.
- Partly but until more funding is set aside for these children to get the real help they need, it is just like sticking a plaster on the problem.

- The critical element is not necessarily the preparation, maintenance or review, but the availability of appropriate services and educational resources to deliver suitable and timely provision. At the moment, I don't think we have these resources in place (eg, limited number of autism educational establishments) and future cuts to non-statutory public sector provision in both education and social services will make matters worse.
- Only if it is maintained as it should be.
- It hasn't so far, to date, has it?
- The Draft Bill assumes that Health and Education can work together within the same timeframes. This does not reflect what is happening in reality. The draft Bill does not consider that the NHS is struggling and children are often not diagnosed with an ASD (for example) until they're in KS2. An IDP for a child WITH an ASD would (presumably) be different from an IDP for a child without an ASD. Because the diagnosis (for an ASD) often happens late, it means that crucial Early Years (best practice ASD) interventions are missed and I believe that the IDP system will not be fit for purpose for such children.
- Not without the employment of more EP's and paediatricians - there is not enough to account for the amount of children with ALN's. Children are not being seen quick enough or often enough.
- I'm unsure that the legal framework is as robust as current statement.
- Still needs discussion with parents and the professionals that work with the young person. Not just experts who often don't meet many of the young people who's lives they can change.
- Because from my own personal circumstances there are too many professionals that don't adhere to what they should and the lack of communication between services and key professionals can be dire.
- Who would be responsible for making sure it was robust and act when it's not????
- The draft bill seems to give a great deal of power to the local authorities and places the wishes and feelings of a young person and family's secondary. It states that children with educational needs should be educated in mainstream schools. How many of these schools have experienced qualified staff? Not many in my experience. How often young people with needs become excluded bullied and suffer with confidence issues that have an effect on their lives into adulthood. Saving local money is always a priority for councils but I would argue not at the expense of young people who given the right education in the relevant educational schools can become productive, confident and happy members of society. I feel the draft needs revisiting and considers more about the individuals and not the saving of funds. Additionally adding NHS into education plans will inevitably hold up young people's planning process while the bodies argue out which service is responsible for what part of a young person's

education. The considerably long waiting lists in CAMHS services will also mean more staff, training in order to achieve a positive outcome. REVISIT AND CONSIDER YOUNG PEOPLE

- No real clarity on funding this additional support
- There just is not the staffing capacity within either the NHS/LAs/schools to meet the demands of the proposed bills and with further cuts to WAG funding anticipated - the situation will get worse not better.
- I am concerned that there will be no legal protection for children with statements. IDPs will be used to reduce ALN provision across all areas.
- I do not know, as I have not been contacted or asked to be involved with this process by local education authority or school
- This is vital that there is consistent approach at all levels of intervention.
- If mainstream schools are able to get away with streaming children with ALNs into the usual catering and military prep courses and have done for years, I really can't see that changing. The school's target system needs to change to also meet the needs of these children and support the teachers that DO have the patience to work with them. My son has effectively been told from Year 7 that he's not good enough and isn't going to get anywhere in life. They gave up on him before they had even started to teach him because he didn't fit in with their targets.
- Need to make clear provision from independent agencies for family support and advice.
- Only if the local authority and schools will allow and welcome follow up and monitoring of input by outside bodies and accept profession input from a TAC meeting or MDT. This may allow for changes in the IDP appropriately.
- Very important that parents have on-going support to ensure the IDP's are properly reviewed and recourse to effective complaint if they are not
- At present the statement is a legal document, and incorporates numerous outside agencies into the mix. IDP has no more legal strength than an IEP. One cannot expect a parent to have faith that their child will have the required legal protection with such a document in place.
- Needs to have specific and quantifiable or we are losing ground
- At the end of the day it still seems that it is down to the individuals in the system to manage it as they choose to and in practice this is very easy for individuals to 'pass the buck' so no realistic culpability is achieved, with often no real progress of action either.

The child is always the loser in this game played by everyone involved and true multiagency working has been even worse in our experience than dealing with an individual, as in practice it just takes much longer and allows more people to say it's someone else not doing something. It is even easier for health to say it is education and vice versa and nothing at all gets achieved.

Until there is someone truly independent chairing and monitoring the

progress, there will be no improvement seen in reality.

Who is assessing the quality and are they independent enough of the agencies involved to truly challenge the things that need to be challenged and elicit action when it is needed?

In reality parents of children with complex problems are often too exhausted in their full-time care role to take a fully judicial route, when really things should never have to get anywhere near that far.

But the true picture of multiagency working is a far cry from the 'ideal' and until this can be ironed out, this route is in fact more risky for those children with complex needs, than more secure.

- I have not actually read though the Bill in detail, but having gone through Part 1 of the Explanatory Memorandum I have some concerns. Firstly, the role of the school and the Local Education Authority isn't clear to me in the process. Secondly, I gather the school will largely be responsible for preparing IDPs. We are fighting at the moment to get a statement for my son and his school, including the SENCO, while broadly supportive, seem to have little understanding of the procedures involved and I would be hugely concerned about lack of expertise to prepare these. It seems to be that SENCO is a responsibility that forms a mandatory part of another post at my son's school and doesn't require the post holder to have any specialist expertise- I wonder how many schools this is replicated in across Wales. I would be concerned about the school preparing an IDP for my son due to this lack of expertise, particularly as I have concerns over the way his IEPs are being both prepared and assessed at the moment. Thirdly, I think the tensions between being statemented or not will just be transferred to tensions over the content of IDPs if statements are scrapped.
- It is not worth the bill at all as there is no legal duty within the framework as in England, it all seriously will fail all SEN children, going back 30yrs ago, appalling consideration to change the dummy's ten without due me care,.
- No, as there's not a financial stream to support it also lack of funding for training to support IDP
- There is insufficient detail on how monitoring will be carried out. The absence of the words detailed, specific and quantifiable mean that a woolly, unenforceable document could be drawn up.
- This is not a robust framework. There needs to be some mention of the need for the details in the IDP to be adequate to meet the child's needs.
- I'm concerned that they may be a lot of work to create and implement and therefore children in the grey areas or with less complex disabilities may be purposely dropped off as the complex cases take up so much time. The Lea are responsible now for creating statements who will be doing the formal legal side of all these IDP's? Will this create an unintentional dislike of children with disabilities due to the workload they create? Will this create an institutional negative perception of this already vulnerable group?

IDP's

- How can we be sure that IDP will not be changed without my knowledge? At present IEP's are changed and I do not sign or be involved in them.
 - IDP should only be changed when everyone involved is there in order to sign and agree. Will I be able to have individual support from the early stages? What transition package is guaranteed?
 - How secure will the IDP be and how will it be shared?
 - IDP should only be updated with parent / carer involvement.
 - IEP now are not reviewed / signed, so what guarantees have we that the new IDP will be?
 - What are the Info Sharing Protocol and how secure and accessible will it be?
 - Transition Planning should be included in IDP.
 - Where will the information be stored and who can view it? Also how long will the information be stored for?
 - Where will out of date information go?
 - Thought timescales would be too onerous where they had many pupils on IDP
 - IDP – one format
 - Will the statement be watered down during changeover to IDP?
 - Disagree that there is a robust framework yet
 - No unified template
 - No requirements around portability and what happens when a child or young person moves into home education or to another establishment or another LA
 - No specificity required
 - No mandatory EP involvement for IDPs that are the responsibility of the LA or those which currently fall under SA+ many of whom require ongoing EP involvement
 - No understanding of the requirements of travelling communities
 - Unclear about how it will work for Home Educated young people as there is no suggestion of a direct payment scheme
- No informed Neutral independent support throughout the process the disagreement avoidance and the independent advocates and case friends are a fragmented approach that could leave families without a unified support system – suggest that all children, young people and families wanting or having an IDP have open access to a unified system of support, advice, guidance and avoidance and resolution of disagreements and that children, young people and families considering dispute resolution prior to or within the appeal to ETW have additional access to independent

advocates and Case friends LA more confident PCP will reduce conflict but saw the process as fragmented and costly

- If replacing IEP and statement, this would not work with only an annual review. The IEP is reviewed and needs to be reviewed more often.
- Who is the governance on completing the IDP's?
- If child says things are ok, they take away support.
- Logistics of preparing IDP's is going to be difficult.
- Because PCP takes so long, I think there will be compromises in preparing them.
- Already IEP meetings are being dropped in some schools and they are just being sent home to be signed – Cuts out parent's involvement.
- Communication between schools and parents already poor.
- Bilingual forms are hard to follow – better to request either English or Welsh separately.
- Already hard to get people, especially professionals, to turn up for meetings – E.g. Annual Review. Will that improve with the new system?
- Think IDP should be single format across Wales and for all children 0-25. Content to vary as per individual.
- IEP 3 times a year; IDP once a year – How could you ensure more regular updates or the introducing of new targets for child as they progress. Action plan needs to be regular updated
- IDP looks very 'nice', but not enough detail on them.
- Re: DLA support evidence – From a statement, would there be enough hidden difficulties to apply for benefits affected? Information is needed to support claim for DLA.
- There is a huge spectrum of needs from one condition to another. There needs to be more detail on IDP.
- Who's going to be responsible for collating all the advices? At least in the statement, the advices are collated and can be referred to as necessary. My child is not receiving the support that has been suggested by the professional.
- IDP has no diagnosis box. This is very important to me as a parent. I need a T/A to pick up straight away what my child's condition is. ASD is so different than Down syndrome.
- IDP is a bit wishy washy for me even given the info in the COP
- Who will receive all the doctor's, SALT and EP reports to feed into the IEP? Do they really think the SENCO will have time to this? They struggle to find the time to discuss my child, as it is, now!

- Some of the focus is on good days and bad days. It's a bit personal. I don't really want to have to describe a bad day to the SENCO. I don't want to focus on the bad days. They are difficult enough as it is, without having to share this information.
- one format- not different in each authority/school
- Felt not all teachers had not enough knowledge to do this well liked the idea of training but not sure that the ALNCo would have the expertise or resources for more complex children
- Will the statement be watered down during changeover to IDP?
- It was thought that at school level it would be inevitable the words such as access too , regular and when available would be used
- Very concerned that this does nothing to ease the problems in getting assessments
- Where do privately funded assessments sit within this set up?
- Yes overwhelmingly liked PCP and IDP's
- Thought timescales would be too onerous where they had many pupils on IDP
- There are no time scaes suggested for notifications of no IDP or for complaints etc
- Felt there needed to be guidance on how much time these might take might need admin support
- Child indicated by facial expressions that she liked the ideal of IDP
- Discussed how important to and important for could become part of every class as could one page profiles
- Concerns around health not engaging in IDP just as they don't now

Severe and Complex Needs

Question 4a

Health provision for children with severe/complex needs *'must be agreed'* by the Local Health Board or NHS Trust before it can be written into an IDP. If you disagree with these decisions, which would you like to access:

71% Independent Avoidance and Resolution of Disagreement service

50% Independent Advocacy for your child

31% NHS complaints process

- Once my child has reached an appropriate age, they should be able to have access to specialised agencies.
- The child / young person should be able to challenge after they reach a certain age, i.e. 16 or 18.
- The sharing of information is an issue. It is needed, but so are robust processes. I like the duty to share information.
- If Health take lead in Pembrokeshire, education reluctant to get behind it. Health and Education don't currently share information in Pembrokeshire, so new, therefore good
- If a child's needs have a medical source, then input should be included in the IDP. The complaints process could be any of those above. But you shouldn't have to go to different places for different elements
- The statement: - Health provision for children with severe/complex needs '*must be agreed*', is a very vague statement.
- I believe an independent advocacy for my child would be more beneficial, as they are not biased.
- Very concerned that this does nothing to ease the problems in getting assessments and the expert view of a child's needs-classroom teachers are not specialists
- Where do privately funded assessments sit within this set up?
- Concerns around health not engaging or only as they see appropriate-really worrying
- Cannot see how having a named person for a health region will be sufficient
- **What is a complex need- who will decide what the criteria for a LA IDP is?**
- Barnwyd mai'r dyletswyddau statudol gwan iawn ar Fyrddau Iechyd yw un o brif wendidau'r ddeddfwriaeth yn enwedig y disgwyliadau o safbwynt cyfrannu i GDU a rhwyddineb gwrthod gwneud hynny neu tynnu darpariaeth y cytunwyd arno'n flaenorol yn ôl.
- Mynegwyd pryder y gall gofynion cyfrinachedd achosi anawsterau i staff Byrddau Iechyd o safbwynt cyfrannu i GDU.
- I think children with very complex, life-limiting conditions will still be well supported. However children with other complex issues will have a weakened provision
- Duty, and a time limit to enforce action.

- I have been waiting for over 2 years for my son to be assessed by CAMHS, now he is permanently excluded from school. The whole waiting for referrals is so frustrating
- This is only going to work if Health agree to fund their side of the agreement from the beginning.
- Personally if I had Children in school under the new system I would most concerned
- There are very little specialists in our area that would know the complex health needs that type 1 diabetes involves for each individual child. Our hospital is in special measures, they will do everything to avoid any extra expense. Their priority would not be to out the child first.
- The process is slow, under staffed and phone calls and paperwork ignored, often parents are blamed and 'behaviours' are put down to diagnosis where nothing is done.
- This needs to be done in a timely manner as it may affect a child's education.
- The education department and medical profession never seem to be singing from the same song sheet.
- I think it would need to be agreed as all bodies involved need to agree and be on the same page, but this can be timely and at the cost or detriment of the child.
- Not sure. Waiting on advice from NHS professional has delayed the support for my child, but health professional's opinions matter. Quick to dismiss from records - frustrating for parents. Parents are the only 'constant'.
- There must be a robust system in place, short time frameworks so the process doesn't drift.
- Complaints procedures are lengthy, traumatic and complex for families and rarely result in a favourable result for the (young or old) person in question.
- With NHS cuts this could take forever.
- The issue that I see with this is the time it is likely to take. Decisions and actions have to be taken quickly. Waiting six months or more for a decision can be a huge percentage of a child's life at that point in time.
- NHS complaints process is a joke. Non-existent. Vastly inferior to e.g. Tesco complaints handling.
- All of the above and more due to my personal circumstances and what we have been through with my son.... For provision to be agreed, meeting panels would have to take place. These don't happen all the time which again means that families have to suffer without support in the interim!
- Again conflicts between Health, Social Services and Education will rise due to pressure placed on them. This has a long history of occurring with any plan for young people with Health insisting the difficulties are social or educational and the other way round for the other services. In the

meanwhile the young person's future is in limbo and often the resolution is based financial considerations only.

- The NHS complaints **process has NO teeth at all**. Where there is conflict, once again independent specialists should be called in. The tribunal service requires generous legal aid funding - far more than at present. As things stand only the rich are likely to have their child's needs met.
- The NHS trust in Wales (south in particular), are discharging their duty from the majority of children with complex needs. With this type of process already in place for quite some time, it is highly unlikely that they will agree to provisions being in place within the IDP
- There will always be disagreements with provisions as it will always come down to money. It's getting worse not better, and because people with difficulties don't have the ability to fight for what they need they are ignored.
- Access to timely independent disagreement service, rights to appeal process and tribunal process
- This is an area of huge controversy if there is a disagreement and complaints to the ombudsman in this instance should be more efficient and sooner.
- The SEN Tribunal should be able to look at provision provided by Health Boards.
- I want my advocate to have a sound knowledge of legislation!
- Our experience is that the Heath Authority just won't agree- as say do not have the staff, resources, time, money etc to cover things a child with complex needs may need and certainly won't agree to provide a service in an educational setting.

It has, in our experience, led to our daughter collapsing as not able to access services and if a complaint is made via Health, they will say they DO NOT cover educational setting as that is 'EDUCATION'.

In reality this makes our children more vulnerable to not having these needs met at all.

We have already experienced this across all 3 sectors, with everyone passing the buck, whilst children with complex needs get steadily worse from not having the appropriate service in at a time necessary. We have had one child with physical/medical crisis due to this and the other with emotional/anxiety crisis.....If the system won't help these vulnerable children now, they won't help them just because it is written in an IDP, it will just end up with a non-agreement and no support.

The only losers are the children!

- I am very wary of internal systems of dealing with complaints as I don't feel they are independent enough to deal with unwritten "informal" procedures an organisation has to deal with cases. All help in these cases should be independent.

- Already in the known system health are not able to provide any of the services, it should be all independent assessment not protocol based that health will only tick box forms, it leads to no proper therapy or written clear medical advice, as many medicals are stopped from writing what they truly feel, this protocol system needs to be abolished between the health & education, more private independent medics should be doing the medicals for the complex needs children and children that are home educated as of complex needs
- There is nothing in these proposals which will mean health or social services will provide ALP. If they agree to provide than it's slightly stronger, but when they are under such pressure and demand for acute services and cancer services ALN won't feature.
- What happened to the proposals in the white and green paper for SENTW to look at Health provision?
- What happened to provision pathways- everybody in earlier consultations liked them parents and professionals alike.

Question 4b

Do you think that the draft Bill is sufficiently robust and would provide the basis for an improvement in the way that agencies work together to deliver good support for children and young people with ALN?

51% Yes

49% No

- In principle it sounds as if it will work, but I would like guarantees or proof of case studies that have worked.
- As long as it's not full of undecipherable jargon – Be specific to each child's individual needs!
- The people agreeing to provide services (Health / Social Services) are the people who are going to provide – so will they not agree if they don't want to provide?
- Parents are currently getting different provision – Provision pathways would be good, so parents know what to expect. Consistency of approach => Equality.
- In Pembrokeshire – only get one diagnosis- Don't assess for other co-morbid conditions a child might have.

- Will the code of practice say 'you must' or 'you will' to ensure provision? Steps the LA 'considers appropriate' - who will make the LA have to make ALN system known?
- Doesn't seem to include all agencies.
- Unsure how all agencies will connect- when even now not all partners attend statutory annual reviews.
- I don't agree that it will be an improvement. Health professionals do not attend my child's Annual Review now. I cannot see them having the capacity or time to be involved in developing the IDP.
- There needs to be a lot more information.
- Medical officers is not new, they used to have them in Swansea.
- There's nothing in these proposals to improve partnership working.
- We sincerely hope, whilst attempting to sort out an old cumbersome system that does not really meet the needs of children who have more than just educational needs, that the new bill won't leave our vulnerable children with complex needs in an even more vulnerable situation than they are now. Whilst multi-agency working makes sense, the fact that all are under staffed and underfunded, means they are not truly in a position to deliver the services these children need now and they certainly are not going to agree for that to be noted in a legal document!

At least currently there is a legal backing for our children with complex needs in an educational setting, but in reality these children are not really protected unless they have parent's with the time, energy, health and money to drag themselves through the legal route.

Without a robust system to ensure that IDPs (or Statements) are not just a paper exercise by the LA, for a school to just choose to cherry-pick what they want to do, rather than what a child is deemed to need, this is still just a paper exercise.

- Anything should be an improvement on current Status Quo, as collaborative working is poor at the moment.
- Yes is answered when considered broadly. The 'devil is in the detail' – The Code of Practice and regulations must be equally robust and provide a non-interpretive frame work for relevant agencies.
- It should, but how is the extra workload involved in communicating with each other possible, without extra staff / funding?
- Anything should be an improvement on current Status Quo, as collaborative working is poor at the moment.

- There needs to be legal redress to make sure support is consistent.
- MUST have a clear timescale and process nothing in the bill to promote or expedite Robust?
- Where are the teeth to make sure LAs adhere to a common, coherent process across wales given that they routinely ignore the current CoP without consequence? What about young people post 16 in non-FE college environments such as work related training, apprenticeships etc. Is the approved list of schools not unlawful? What happens to new institutions and providers? What if the support a child needs cannot be provided in wales - for instance if they have to spend time at GOSH or other UK centre of excellence hospital?
- I fear that the draft bill will mean that children with learning difficulties, autism, ADHD, anxiety, attachment disorders, etc. will get "lost in the system"
- I believe that this is another attempt to force agencies to work together and parents need a legal document that is binding and clear and need one agency to deal with not several as this might happen.
- Children can be so individual so no blanket written care plan can be appropriate for all children
- They seem to work well together if they want to block things already (personal experience) what is need is a strong independent review panel that can enforce decisions.
- I don't think the moderation panels in the draft COP will do this they will not be independent.
- Health needs have been almost dismissed totally from the plan. This is unacceptable.
- Again not very easy to know if it will be or not unless it has a trial run.
- It's too woolly
- Not sure we hope it would but needs to be in forcible- don't think this is stronger
- I would be concerned that certain bodies would be doing more than their share or not able to agree with the other bodies concerned, this could be detrimental to the child. Time is of the essence, as when needing to put things in place for a child that needs support, for whatever reasons, it is essential that this starts as soon as possible. If there were termly meetings the parents would feel more involved and supported. Also, these plans need revising more regularly as children change at a faster rate, some objectives on the plans may be met sooner and need more targets. Communication is

key, this communication should be regular between all parties! This Bill can only be robust if all of the above has been adhered to.

- Agencies need to work together with parents and follow things through.
- I work in health. I am aware of the difficulties getting all appropriate multi agencies together at the same time. I am worried about data protection.
- Independent agencies would have to work together and be totally unbiased.
- YES but the children's needs must be kept up to date. e.g. my daughter needs speech therapy there is none available for her at the moment even though she received it up until 2yrs ago when it stopped as no replacement for the speech therapist was made when the current one left the position
- It is in such a state and agencies are in poor practice of working together. Trust has been broken across all agencies. Parents have historically been battling for services which they were already entitled to, but not getting. People don't believe there is going to be change. It's going to take a lot of change to make any difference. I'm not optimistic. Also there is not money to support any of this new initiative??
- It's an improvement but more could be done.
- Agencies already do all they can to join the dots, but they are already spread too thinly to effectively work together. This seems to be more challenging as your child gets older - into adulthood. Potential closure of support services due to budgetary issues would make this worse.
- I don't know
- At present, it is extremely difficult to get all agencies together to provide the support required.
- No idea
- Agencies rarely work together. Often the right hand has no idea what the left hand has put in place, nor the framework to work with it or implement it, without the kid and parent going all round the loop all over again.
- I don't know, I hope so
- Not unless more EP's are provided to cover the cases and deal with the backlog of children waiting.
- Don't know
- It would provide a basis but in my painful experience, there is a hell of a long way to go for multi=agency working to be effective and efficient in ALN. I am a midwife and so have experience in multi-agency working and would fear for my PIN if I was as ineffective and incompetent as those attempting multi-agency working that I have experienced in my fight to get my son's additional learning needs met. It has been the biggest eye opener of my working life. You have an extremely long way to go and a lot of lessons to learn.
- needs to be proven
- Nothing is ever robust! Until the plan is put in place and followed by all...
The true outcomes will not be known. How many more times do we have to

hear from professionals / services? We need to learn from these mistakes. Children and young adults with ALN and complex difficulties are humans with rights that need support as well as their families. However let's not forget that as robust as the bill maybe.... It all comes down to money in the end which is being cut dramatically from budgets and much needed services.

- Not specific enough - who is accountable?
- It is not clear how agencies will link together to make it effective as possible. Most staff are currently over worked and departments do not have sufficient funding to put all new practices in place in best possible way and provide relevant training for all staff.
- There is NO identified key worker to co-ordinate across all agencies with real accountability if this does not happen. Parents will be forced into the role and many simply do not have the time or training needed
- The implementation needs to be robust and not used as a tool to reduce support
- Nothing ever will be, people will still fall between the cracks of funding and people who literally can't be bothered to do their jobs properly. I have seen it happen again and again.
- Having worked within the education sector working with early years children. I find it increasingly difficult to get clear pictures of certain children. Professionals should work together with the child and parents to develop a robust programme for individual needs. Confidentiality at times puts up walls between the different services which prevents us moving forward with individuals.
- More communication between two parties is needed
- Makes no difference!
- Different agencies need to have a legal and time bound requirements ensure recruitment and identified staff to work together with other service providers
- Consistency is required and joint working with NHS & LA is proven to have its benefits and will deter schools from working alone and obstructing provision on the basis that they don't understand ALN of a child as the diagnoses are out of their experience. The child's needs are bigger than any one school or body and working together is imperative in improving support provision.
- If the bill is followed it should work but many LA fail to inform or support and accessing 'excellent support' should be the norm rather than the unusual
- very hard to get agencies together
- It is too reliant on only 'goodwill' and 'IF' agencies agree to accept responsibility and then 'IF' they then actually do anything about it, rather than it just being a paper exercise.

Where is the independent chair who is holding them to account at the point of usage of the service?

...i.e. where the child needs it, rather than exhausted parents having to go through multiple complaints procedures to elicit the care and support their child with significant needs should be entitled as a basic Human Right!

- It is a source of great frustration to me that there is little co-ordination or information sharing between the NHS and the school/ LEA, with me feeling I have to act as go-between. However, paragraph 3.78 of the Explanatory Memorandum seems to suggest a very wide ranging ability to get out of helping or sharing information. Why can't it just be part of these organisations duties?
- As they fail to meet as in MDT's now, they can't work as a team to provide, there is no communication between all the agencies
- As there is no additional funding and no plans for training
- With no extra resources I fail to see how the additional time and resources this would require can possibly be provided. Unfortunately this means that although the theory is great it will just end up being pretty words
- This has been needed for a long time. It will hopefully prevent my son be dissected and his difficulties seen in isolation of each difficulty depending on who I've seen.

Health have neglected their responsibility of providing what my son needs and this will hold them accountable.

Information, Advice and Support

Question 5

How are parent's best supported to participate in decisions about their child?

46% Given written and spoken information from the school/college & local authority

13% Access to an Independent Advocate (who does not necessarily have specialist knowledge of the regulation and legal aspects of education)

90% Advice, advocacy and support from an independent service, not related to the local authority (with specialist knowledge of the regulation and legal aspects of education)

- Independent Service who will stand together with us parents.
- It is important as a parent to have the opportunity to speak to someone independently to make an informed decision.
- Independent Parent Partnerships should be made available as routine.

- Local Authorities should be obliged to provide information and in a variety of formats, including spoken. It is not enough though and independent advice and support is also needed.
- It should not be a duty to provide information and advice “as appropriate”, there should be set standards, including minimum standards. In concerned a LA will just add a bit to what are already very poor websites.
- It is really important for families to have independent advice and support. When you have a child with ALN and complexities, everything becomes a minefield. Paperwork is not usually easy to follow and professionals and services need to think about readability and use easier words.
- Essential that service such as SNAP Cymru are maintained it is very important that parents receive INDEPENDANT advice separate from the LA
- Help and support from school, college as well as outside agencies such as Speech and Language therapy, Occupational therapy, physiotherapy, social services, educational psychologist are essential. It is inadequate to concentrate solely on a young person’s educational needs when health and social care issues often need to be taken into account when providing support. Multi-agency approach is necessary.
- Help and support from the school, LEA and an independent person, but also time given to seek own advice, e.g. legal advice, if considered necessary
- From local authority given assessment only not schools or collages
- Family officers and liaison officers are ok but not independent, they can be positive but for complete transparency and trust the information should be independent of the LA as proposed for the disagreement resolution services.
- O safbwynt cyngor a chynhaliaeth i deuluoedd, mynegwyd y farn yn gryf mai gwasanaeth annibynnol a hyd braich oddi wrth ALL y dylai fod. Pwysleisiwyd bwysigrwydd gwasanaeth o’r fath i deuluoedd bregus a rhieni a all fod ag anawsterau dysgu eu hunain.
- Pwysleisiwyd yr angen i wasanaethau eiriolaeth ar gyfer plant a phobl ifanc gydnabod oed ac aeddfedrwydd.
- Pwysleisiwyd bwysigrwydd gwasanaethau rhiantu megis Portage a mynegwyd pryder bod gwasanaethau allweddol o’r fath dan fygythiad gan y’u noddur yn aml trwy gymorthdaliadau penodol.
- Pwysleisiwyd bwysigrwydd sicrhau bod yr holl wasanaethau a darpariaethau ar gael trwy gyfrwng y Gymraeg ar draws Cymru oherwydd mae diffygion sylweddol yn hyn o beth.

- Communication and input from school / local authority and support / advisory / independent organisations and SNAP Cymru!
- It's crucial that parents are supported by someone who understands ALN / SEN and the systems in place.
- Advice, advocacy and support, needs to be impartial and independent
- Yes is answered when considered broadly. The 'devil is in the detail' – The Code of Practice and regulations must be equally robust and provide a non-interpretive frame work for relevant agencies.
- Independent advice is key. It must be without organisational or sectorial bias and focused on the child and family.
- It should, but how is the extra workload involved in communicating with each other possible, without extra staff / funding?
- This is essential for fairness across the whole range of people needing help.
- Independent service support – otherwise support would not be comparable for families.
- Did not want to rely on school or LA for information – felt both school and LA had a vested interest in disinformation and misinformation as they had to gate keep scarce resources.
- Wanted information giver to be independent and able to give advice and rights and responsibilities within the legislation and regulations
- Wanted expert advocacy either in the area of ALN presenting or the Education Law or to have access to both. Saw the value of being able to take a friend to meetings for support
- COMMUNICATION IS KEY YET IS THE SINGLE BIGGEST STUMBLING BLOCK IN SUPPORTING OUR CHILDREN WITH COMPLEX NEEDS.
- At present the funding for advocacy does not match the need so there is no immediate advice available, you have to wait for days for someone to call, and no assistance with tribunals etc.
- Written and spoken information to my experience is never given to the parent's until it's too late to do anything about it or never given until asked.
- It HAS to be INDEPENDENT and is HAS to be their RIGHT! And access to it should be PROMOTED, not just something a parent has to hunt around looking for!
- Easy access to independent experts in the field of whatever problems the child has as it was the only way we got anywhere.
- I find the current system in Pembrokeshire where the Autism Outreach Team and Team around the Family who all claim to be impartial, yet are employed under the umbrella of Pembs CC, to be unacceptable.

- How can Pembrokeshire call their advice impartial! Nonsense!
- SNAP CYMRU are absolutely amazing.
- As much help and information available from everyone but it has to be accurate
- For us - snap Cymru
- The LEA and school and other services that are involved should be on the same page and have the same information, working towards the same targets/goals. Parents can be overwhelmed by all the parties involved and therefore it is best to have a termly meeting with all those involved at the school that the child attends. This is not only informative to the child or family, but to those who work with them and support their learning.
- Schools struggle to give parents information that they require. It is not discussed, parents are not involved - no time and no opinion regarding education in my experience. Teachers and other professionals are experts in their areas but they need to listen to parents - they know the child best. Every parent with a child who has ALN should have a school contact to discuss any queries, concerns - to ease pressure on teachers but allows the parent to be involved so they can meet the needs for the child at home. Without this, creates a barrier. Not good. All must work together and give as much information as possible - especially when your child has a communication disorder - parents in this case RELY so much on the school to have effective communication methods so the child can progress and treated fairly.
- I had no help/advice from the LA regarding my son, quite the opposite. Only advice was from a friend who also suggested I get in touch with SNAP Cymru.
- Local support groups are much valued by local people, but are underfunded and our nearest Parents & Carers Forum is about to close.
- Currently SNAP Cymru are the best at offering this service. All services must be available to home educated children too as there currently appears to be no set guidelines on obtaining SEN support for children who are not educated within a school.
- Local authority funding of so called 'independent' advocacy services is probably necessary - but still a conflict of interest all the same.
- There is a severe lack of support for parents, information is not relayed clearly to parents and therefore they are ill informed or simply do not understand the processes.
Independent services must be more available to support parents - i.e. provide more funding to SNAP Cymru.
- This is absolutely crucial. In my experience the present system enables the Education Authority to pay only lip service to obtaining advocacy for young people with ALN, let alone their parents.

- Also in my experience, the crux of the problem with ALN education lies in the dearth of suitable placements.
- I was actually told by the LEA when I was fighting against them when they wanted to send my son to an extremely unsuitable school, "This is Special Needs Education. We aren't looking for excellence as in mainstream, we are looking for good enough"!!! An absolutely abhorrent statement to make, as well as being wholly discriminatory to my child.
- I need independent support to also be involved and included in meetings regarding decisions about their child
- SNAP Cymru- At least they are then impartial.
- All parents need to be able to consider options available to their children and be given information about their child's needs regarding education, this should be undertaken by an independent person not employed by any of the services who are responsible for provision.
- Such as SNAP Cymru - an excellent support service!
- You need both because to many people just drop the ball. We have suffered greatly because we were not told different things (again nothing to do with Snap who have been great with us).
- It is so important that verbal interaction is set up between the child/parents/authority. Individuals are all different.
- Such as SNAP Cymru or other Independent (not in house) suitably qualified parent partnership services
- Both school and independent body with knowledge should work together with the parents to ensure all aspects of the Childs well-being and learning is understand and planned effectively.
- I don't think an advocate without specialist knowledge would be safe...

- INDEPENDANT & SPECIALIST are the 2 key words here
- Parents need access to independent advice as the LA will often give 'advice' that suits their purposes.
- must have specialist knowledge no good without-education law specialism
- AND THEY HAVE TO BE TRULY 100% INDEPENDENT
AS IF THEY ARE RELIANT ON THE CONTRACT FOR INDEPENDENT ADVOCACY FROM THE L.A. ITSELF, ARE THEY TRULY INDEPENDENT AND HOW FAR WOULD THEY PUSH THE L.A. IF THEY HAD TO?
- Having been given what I feel is largely self-interested information from the school and LEA about my son's case and batted back and forth between the two, I feel access to independent advice is important.
- Independent advice is vital, but a case friend for a child with complex needs must be the parent only as they know their child best , more than anybody else, rare conditions and unknown syndromes currently are being seriously failed, as dictatorship is through schools, this is not acceptable as support is required in many areas

- Independent advocacy and specialist advice & support are essential
- Someone independent that can support parents and without any connection to lea to ensure no connected agenda can be followed. Parents are extremely vulnerable in the complex system. I am a teacher myself and it confuses me. I found my sons disability social worker was a great independent support and has never lost sight that it was my child that was important and his best interests.

Question 6

What's the best way to provide information and support for children and young people to enable them to participate fully in decisions about them?

- 44%** Give written and spoken information from school/college or local authority
- 12%** Access to an Independent Advocate (who does not necessarily have specialist knowledge of the regulation and legal aspects of education)
- 45%** Through having access to a 'Case Friend'
- 22%** Through having access to an Independent Disagreement Avoidance and Resolution service with knowledge of the systems
- 80%** Comprehensive advice, advocacy and disagreement resolution from an independent service, not related to the local authority (with specialist knowledge of the regulation and legal aspects of education)

- We need someone independent who we can trust to provide impartial advice- a family officer, engagement officer or liaison officer can't do this
- If the child is intellectually capable, then having information verbally explained by a familiar person is the best option.
- The supporter must have good knowledge of ALN and systems to be able to fully support a child and young person.
- Advice, advocacy and support, needs to be impartial and also specialist knowledge of the regulation and legal aspects, as education is crucial.
- Advice and Information must be provided in a way that does not lead or influence those it is given to. Only independent advice - meaning away from LA based services and offices.
- Support is needed for children who are unable to understand the impact of their decisions.

- Currently SNAP Cymru are the best at offering this service. All services must be available to home educated children too as there currently appears to be no set guidelines on obtaining SEN support for children who are not educated within a school.
- In all cases of complex needs and home education of children with rare conditions and Unknown syndromes. Much more professionals need to be supportive in getting all services required for the families, be independent legal advisors in helping navigate the system only.
- Croesawyd hyn ac yn dilyn trafodaeth nodwyd yr angen am gynhafiaeth hefo casglu eu barn. Awgrymwyd y canlynol:
 - Maent yn croesawu cynnwys rhestr o bobl broffesiynol sy'n eu cynorthwyo. O safbwynt addewidion, maent o'r farn bod angen eu cynnwys ond rhaid hefyd eu hanrhydeddu er mwyn sicrhau atebolrwydd.
 - Rydyn ni eisiau i'r holl blant, pobl ifanc a rhieni/gofalwyr gael yr hawl i apelio os oes angen hynny.
 - Trafodwyd enghreifftiau mae'r bobl ifanc wëid ei phrofi yn barod, gan gynnwys person ifanc ddim yn cytuno am ddarpariaeth arbenigol dyslecsia wedi ei ddiddymu a pherson ifanc arall ddim yn fodlon hefo'r lefel o gefnogaeth gan gymhorthydd. Yn y system bresennol nad oeddynt yn medru codi cwyn ac felly yn croesawu'r hawl sy'n galluogi hyn.
 - Cytunwyd y bydd mwy o gyfleodd drwy ddull person canolog o adnabod problemau ac i atal anghydfodau posib. Ond maent yn gweld y gall anghydfod godi os yw eu barn hwynt a barn eu rhieni'n wahanol e.e. gostwng lefel cymorth, teimlwyd bod angen felly am gefnogaeth profiadol a phroffesiynol ar gyfer paratoi, esbonio, amlinellu dewisiadau a chyflwyno ar ei gyfer os bydd cwyn/apêl yn cael ei ffurfioli.
 - Awgrymwyd dylid neilltuo'r Tribiwnlys ar gyfer materion allweddol gan sefydlu trefn gwyno leol ar gyfer datrys y mwyafrif o faterion.
- I think school and college should be the best way but I also believe that it depends on the school. Independent advice should be included also where needed
- Will independent advice be made available to parents from Early Years?
- id not want to rely on school or LA for information – felt both school and LA had a vested interest in disinformation and misinformation as they had to gate keep scarce resources.
- Wanted information giver to be independent and able to give advice and rights and responsibilities within the legislation and regulations
- Wanted expert advocacy either in the area of ALN presenting or the Education Law or to have access to both. Saw the value of being able to take a friend to meetings for support

- Wanted the same supporter from the start of the process through to SENTW if needed.
 - Saw the value of disagreement resolution but too little too late
 - Did not think avoidance of disagreement would work unless linked to independent advice giving service.
 - Wanted free access did not want to wait to be preferred
 - MUST have a clear timescale and process nothing in the bill to promote or expedite
-
- Information in a format that suits the young person - text, email, social media, face-to-face support from an independent advocate who they feel comfortable with
 - The information should be clear in written form and easy to understand at the meetings, this is to allow the child to be involved in the decisions and also for the parents to easier understand!
 - All should be available. The code of practice is not followed correctly - lack of funds, staff shortage is not the child's fault. ALN pupils have as much rights as any other child and should be treated fairly/ equally. Not be excluded because of their difficulties - gain knowledge from parents - works both ways.
 - Needs to be independent advocate system with knowledge with the focus on the needs of the child and the legal responsibility organisations have to support some of the most vulnerable children to ensure best outcomes
 - Vulnerable young people need to receive important information from people they know and trust. A stranger introduced into their lives may have to wait a long time before they are trusted.
 - Independent accurate and informed-This is essential. Anything less is not doing justice to these young people. It would be a waste of time and money and an insult to those young people.
 - Would have to fully understand how to work with children and young people who have difficulties and who may not understand. Think about how best they can work with the individual by working with the family to understand fully how to work with them. One size does not fill all!
 - Each young person needs to feel safe and secure with whoever is going to guide them through the process. Gaining trust takes time and effort on the part of any advocate. I feel that children need to be given a choice and be heard. If the nominated person has limited knowledge of the law then it should be up to services to provide information and options open to the young person
 - It can't just be one group of people as something vital could be missed and will be missed

- Appropriately qualified and informed person, specifically employed independently to LA/HB, as a legal requirement for all LA's
- Both school face to face with someone the child trusts and knows and an independent person assigned to the child early in case there are problems with the provision.
- Essential children and YP when possible are allowed to make decisions often parent fixed on their plans and their sons and daughters not consulted
- All of these are important but an independent, comprehensive, specialist advice, advocacy & disagreement resolution service is essential. Independence is crucial. Many of us have had very difficult experiences with schools & LEAs so it is hard for us to trust that they will give all the relevant information.
- Someone who knows the child eg teacher or teaching assistant as they know them best. And verbally explained and then their responses should be recorded.
And these options should be taken very seriously and passed on if a child is unhappy.
- Early independent advice so that disagreements don't happen in the first place

Avoidance and Resolution of Disagreements

Question 7

What do you think is the best way to avoid disagreements with schools/colleges and local authorities?

77% Access to an independent information & advice service with knowledge of the education legal system '*at the start of any decision making process*'

25% Access to an independent information & advice service with knowledge of the education legal system '*at the point when things start to go wrong*'

58% Access to a named local authority family officer '*throughout the process*'

16% Access to an Independent Advocate/Case Friend (with no ALN specialism) whilst considering making an appeal to the ALN Tribunal

10% Through other means

- Key worker who knows particularly in the EY's
- These options aren't mutually exclusive. LA's need to be good sources of information, but independent advice is vital too for trust
- Communication and any information sharing is good.

- Saw the value of disagreement resolution but too little too late
- Did not think avoidance of disagreement would work unless linked to independent advice giving service.
- Wanted free access did not want to wait to be referred
- MUST have a clear timescale and process nothing in the bill to promote or expedite

- Allow parents to have a say and have their opinions taken on board by professionals. PP process is good, if used effectively

- **I think** Expert support needed at an early stage
- Disagree if it only comes into action once there is disagreement – how can you rely on schools accessing avoidance of disagreement support early?
- DRS should be open access i.e. that a young person or family doesn't have to be referred in

- Access to independent information & advice with knowledge of the education system at the start of any decision making process, should be from the beginning!

- Better communication between school and parents is needed to prevent disagreements occurring

- Need access to independent advice, as it's too late when things start to go wrong. Im worried schools and LA wont call them in early enough- there's no incentive for them to do so

- LA's need to be far more transparent with parents during the process. Often specialist provisions are never talked about with parents and then are thrown at them at the last minute. If you prepared parents for the possibility of their child needing specialist provision, it wouldn't be such a shock to them, if and when it happens.

- System needs to be transparent. It is difficult time when you are told that your child has additional needs. I initially trusted the school system. Thinking it would be needs centred. I was wrong, staff and senco had a poor understanding of my child's needs and how to support him. He was allowed to drift for three years. It was only when I read the sen code of practice I realised they were not following the code. The LA psychologist seemed to collude with the school. My child's needs were only addressed when I challenged the system. It would have been helpful

from the beginning to have advice / support from an independent organisation about what to expect and how to move forward.

- I have experience of dealing with a disagreement with the local education authority and found the service offered by SNAP Cymru to be of great help as I progressed through the appeal process (fortunately, the LA saw sense before it went to a hearing).
 - Access to an independent and thoroughly trained ALN specialist 'advocate' who knows the family.
 - Through a lawyer/solicitor with extensive knowledge of ALN law, Children's Rights and Human Rights.
 - The process must be made clear and transparent from day one and parents supported fully.
 - Plus given knowledge about the ombudsman, SENTW etc
 - Ensuring that each step of the process is undertaken correctly and efficiently with consideration firstly being for the young person the process about. Additionally all parties involved need at some point to meet the young person (not in a group, as that would be too intimidating) in order they have a face and person in mind when the time comes to make decisions.
 - It can be frustrating when you have a complaint about school because they close ranks on you. I had to take my son's school to tribunal and although they would not admit fault, they changed their school policy which I class as a success.
 - There should always be plenty of groups to help. Life is hard enough as it is
 - independent advocacy and support throughout process as legal requirement across LA's
 - It's important to have a dialogue with the school or LA but in doing so with independent advice from a knowledgeable body.
 - To have an informed participation you need accurate and independent information from the start.
 - We actually needed access to better information from the school and better advice and information much earlier than the start of any decision making process. I feel the school have been deliberately keeping me in the dark for at least two years.
 - 'at the start' this will enable parents and pupils to make FULLY INFORMED decisions and may avoids future disagreements website and helpline such as SNAP Cymru give lots of information/advice
 - The ALN Tribunal would be most appropriate to deal with any disagreements as it is entirely independent. Fund them more
 - An independent person with an understanding of the educational system, but who is truly independent of the LA/school.
- Our experience of a named Family Officer is that they have not returned

e-mails or phone calls, so only worth having if it is someone truly prepared to support you and again totally independent, as they are employed by the people you have a disagreement with!

- Of note, though, with the current Statement system, we actually found the Statementing officer to be our first point of call and worked to resolve any issues we had when setting up the Statement and this worked very well.

However, where the system has totally failed both our children, is not being able to get school's to action Statements etc and nothing tried seems to have worked, so there needs to be a totally different level of resolution, as it make no sense to have to go down the legal route from anyone's angle, if only people would take ownership of their responsibilities to make things work, or take appropriate and timely action to resolve if issues arise preventing this.

- Access only an independent legal advise in supporting complex needs
- Parents also need to understand that their child may or 'need' what they want. And sometimes their demands may not be in the best interest eg I hear a lot of parents saying I want a 1:1 but don't understand the consequences on a child's own independence and growth.

Question 8

The Bill offers three aspects of independent parent and child/young person support (access to Disagreement Avoidance and Independent Advocacy for Children and Young people, Case Friend) – do you think:

7% This would be sufficient

56% I would prefer if the local authority *also* has a Family Officer who will give me accurate, neutral advice about my options

67% I would want to have early independent advice to prevent potential disagreements

- Having a face to speak to is better than dealing with matters by mail or telephone.
- LA's cannot provide 'neutral' advice – even with effort, it will be tainted by organisational priorities, budget pressures and so on.
- Early independent advice to prevent potential disagreements, as long as advice is independent.
- Compliance oversight – ESTYN? Ombudsman? SENTW?
- How can the LA advice and guidance service be independent and therefore trusted by families to be impartial?

- Can children / families self-refer to an advocacy service? Can they choose their own service or must they use LA services?
- At what time can a parent access an independent service – at the beginning or later as and when disagreements escalate
- Many parents do not receive adequate information, too much emphasis is placed on schools to give guidance, and often guidance is steered to the schools needs rather than child and family.

- Nodwyd cyfathrebu rhwng ysgolion a rhieni fel factor allweddol.
- Rhagwelwyd gwrthdaro rhwng ysgolion ac Awdurdodau Lleol o safbwynt cyfrifoldeb am GDU, yn enwedig oddi mewn i hinsawdd o doriadau cyllidol sylweddol, gyda rhein'n cael eu dal yn y canol. Gresynwyd nad oes bwriad gan Lywodraeth Cymru, fe ymddengys, i lunio meini prawf cenedlaethol er mwyn diffinio cyfrifoldebau y naill a'r llall yn eglur.
-
- Parent's Partnership should be in the Bill, as parents need help and support too, e.g. SNAP Cymru.
- When CYP reaches 16, will parents still be involved in their plan, as now they are able to make their own decisions without parental consent and how will this be implemented?
- Where is the Government incentive to involve parents in the decision making

- Must be independent and expert
- Must have thorough knowledge to be able to advocate and advise in one package
- Like the idea of a NAMED LA Officer find it difficult to get any response from a "Team"-how independent tho?
- MUST have timescales and protocols for advising parents of delays and difficulties
- MUST have a clear timescale and process

- Anyone employed and appointed by the lea would be judgemental and have a conflict of interest.
- Any one from the school or local authority i have dealt with has always been biased to them
- I think it is vital to have a neutral body to be able to organise and liaise on behalf of the family.

- Someone else needs to be appointed as a 'constant' to help parents. Different situations, different schools, various problem, no supportive parents and supportive. There needs to be more support.
- Independent advice is the only way to ensure a child's needs are central and met. Professionals should not have a problem with this if they are working within the bill.
- Families need to know about independent advice and where they can go. In my own experience you can't always believe everything you are told.
- All disagreements are difficult but it seems that those bringing a disagreement are subjected to a format delivered by services. I would want early advice, that is the information of appeal process, plus an independent chair person who has knowledge experience and is qualified to chair the meeting. The young person and their family should have the opportunity to specify their preference regarding the structure of the appeal meeting. It might help to have all meetings recorded in order for families to be given the opportunity to re run what occurred as very often the anxiety of meeting to individuals less used to them can become overwhelming and block them from remembering what took place and how they might proceed if need be.
- We all need a large amount of support and help
- Helpful to have ' has a Family Officer who will give me accurate, neutral advice about my options'- but needs to be employed independently of LA
- I believe having a dialogue with the LA is important but in addition having independent advice for support.
- Early advice and support best
- There is an urgent need for a truly independent advocate for child/family at an early stage and for all parties involved to be honest enough to explain what they can or cannot do, so a solution can be attempted, rather than just wait until it all fails, which wastes so much time and in our experience the knock-on medical and emotional, let alone education back-lash is enormous.
These are our children's lives now and their futures at stake!
- If a family officer was able to help manage all aspects of complex needs that would be a great help. My son has complex needs and I feel I am left to project manage a range of health and education professionals that are involved with little help or support. I have found there is little help on offer to negotiate the system, inconsistent advice and a lot of being told that it is someone else's responsibility. To this end, I would have really valued some early, independent advice.
- Without independent early advice there is much more likelihood of disagreement. As well as wasting resources this adds an additional strain on families which are often already stretched to their limit.

- As long as the use of them wasn't confusing and each role was simple and easily accessible.

Question 9

Are there any further comments you wish to make?

The Term 'ALN' & Age range

- I think it is a much nicer name and I am pleased that the age range is higher.
- It's less of a stigma. Age range enables continuity of care and provision.
- Agree age range – very positive for transition
- The term covers learning needs and doesn't mention health or social needs. Is this because there is a weakening of their responsibilities.
- Disagree that the bill will deal properly with the age ranges it sets out to capture
 - ALN is a good name to use instead of SEN
- The term additional learning needs seems very school focussed and doesn't really link to development in the early years.
- Making resources like EP's stretch to meet needs throughout the age range may be difficult-are there sufficient professionals
- Thought the new term was to cover holistic needs-ALN doesn't.

ADY.

- Ai canolbwyntio ar anghenion dysgu, yn hytrach nag ar anghenion eraill fel iechyd, ydy ffordd iawn o fynd ati?
- Cytunwyd mae ADY yn well na AAA. Roedd hefyd cytundeb bod y disgrifiad yn berthnasol i osod targedau addysgol.

Early Years

- No detail for early years feels like an add on
- No understanding of the patchwork nature of possible provision so still a postcode lottery
- **No clear referral route for early years**
- No detail for early years feels like an add on
- No understanding of the patchwork nature of possible provision so still a postcode lottery
- No clear ALNCo type input for 0-3 – suggest making appointment of Key worker or Key Working professional mandatory
- No clear responsibility for sourcing ALP in a timely manner suggest anything that is important for use outside the home in pre-school settings is automatically the LA's responsibility and a push to get home and SSD to fund home based equipment may be an item for the code not the bill

- No clear methodology for a young person to start FE after a period outside school – possibly in a different LA
- No clear routes to assessments for anyone but particularly pre and post statutory education
- Adnabuwyd bod yr oedran 0-25 yn bositif yn unol â'r angen.
- No mention of referral routes from pre-school settings

Funding

- Who scrutinises the Budget for ALN?
- What guarantees will we have that the school will use the money for ALN?
- It should be ring fenced and monitored by an outside source.
- Who'll be monitoring the schools? Budget spend.
- Who will be monitoring the way the school spends the budget x 4?
- What scrutiny is there for school based decisions and school based budgets?
- There's need for transparency and even league tables of schools in terms of their provision for ALN – they exist for everything else!
- LA's argue now about the funding of provision, parents shouldn't be in the middle of this- school blame the LA for not funding-LA says the budget is already in the school
- What guarantees have parents got that the provision their child has won't be affected during the changeover.
- I'm concerned about the financial support and impact of this, as families need evidence to prove we should be entitled to this.
- Concern that this is not a resource neutral process
- LA funding cuts – How realistic is implementation of these changes. A lot of promises / aspiration in Bill, but practically, how will it be implemented / sustained?
- ALN budget going to schools directly – Not ring fenced. How do you resolve issue if school don't fund?
- Who monitors how schools spend their money?
- Even the school governors I know say the LA doesn't provide enough funding despite the LA saying the funding going to the school
- I disagree that funding for ALN should go directly to schools. How does this Bill ensure that children with ALN can go to the school that will BEST MEET THEIR NEEDS? This is particularly the case for children who could, with the right support and expertise, attend a mainstream school. As I see it, there will be no 'incentive' for a school to take children out of their catchment area as a child with ALN no longer carries or attracts funding.

- Who monitors what schools spend money on- can LA's take back underspend or challenge schools?
- What do they spend on assessments and training for staff-they should report on this and be held to account

Scrutiny

- Insufficient scrutiny-why can't ESTYN and SENTW and possibly care standards scrutinise the system.
- Monitoring groups locally is insufficiently independent
- Where there are school-based decisions, there must be robust systems of scrutiny, so that funding reaches where it should.
- There is need for independent advice for parents and service-users to access – in all aspects of provision, even given improved rights of challenge to and request for review of decisions.
- Parents not seeing information in current documents and plans- schools changing things without consent / knowledge.

PCP tools and approaches

- Yes overwhelmingly liked by everyone
- EP saw it as advantageous as part of annual review process and genuinely bringing down confrontation and anxiety
- Felt teachers had not enough knowledge to do this well -liked the idea of training but not sure that the ALNCo would have the expertise, time or resources for more complex children
- EP assured agencies this was not intended however saw EP service as further endangered and spread even thinner
- Schools need more training in ALN.
- Teachers should be given a bit more leeway to treat my son's needs.
- Some schools are better at listening to parents than others.
- I don't think it will be beneficial unless professionals take on all parts, instead of merely what is significant to them.

High aspirations & Improved outcomes

- Agree that there are high aspirations
- Agree that PSP is a format that goes further to promote the interests of children and young people be
- Most additional learning provision is currently within the age range 3-16 (school and nursery age) there are reports that currently 3 and 4 year olds are being supported mainly through pre-school provision because the nurseries cannot get timely support and that charitable and other

independent providers of pre-school support do not have access to an adequate support system

- To extend to 18 would increase the numbers by one third
- To extend to 0-25 almost doubles the 3-16 numbers

Educated Otherwise

- Home and privately educated children are currently not usually given ALP even when ALN is identified through statement-not sure this will improve the situation
- Many travelling families find it difficult to get needs assessed and met
- The needs of LAC and adopted children and young people are not given any special consideration – **I think** the threshold for IDP should be lowered for these groups as escalation in need can happen very swiftly particularly during transitions

Placement

- The presumption of a mainstream place is not mitigated by the needs of the child or young person
- There is a note that the parent or young person may request specialist placement
- Concern that the current preference for mainstream is causing a great deal of school refusal amongst those children who have anxiety as part of their ALN and that there is insufficient or no provision to meet their needs
 - Great concerns about the weakening of parental preference as exists now
- Emphasis has definitely moved away from parents

Increased collaboration

- Disagree this bill as proposed will lead to increased collaboration
- Different systems, descriptors of what is a child or young person, and different government led priorities do not currently support joint working and joint commissioning
- Austerity cuts will make this worse and there is nothing in the legislation to protect resources let alone increase them

Disagreements and appeals

- Agree if it is constituted as a unified and universal service. Funding is key and a service that supports the whole of Wales equally, is necessary
- Concern that the need for appeal to SENTW will not come directly at the stage of identifying whether a child or young person has ALN as there is no route to external validation of the decision taken by schools and LAs. Significant applies to 22+% of these children and young people and

cannot be given a timed definition as what is a significant or likely to cause a significant delay in a new-born will be different to a school child or a young person. Professionals in the fields of health, social care and education can investigate and advise, but the routes to these investigations are not clear and the timescales often vary in the support becoming available. We need to ensure that the needs of children and young people do not become medically led

- Scenario - A school has 60 pupils on the ALN list. The school holds IDP meetings and deploys its internal resources to cover the needs of these pupils. During the first term of the school year several more children arrive in the school having ALN. The school cannot meet the ALN needs of these children and has no flexibility to move support away from the cohort of children with IDPs as the ALP has been written into their plans and agreed and forms a legal contract. The school refers this to the LA to take ownership of the ALP. This could happen in half the schools across a LA
- .Some children will just go along with advice of ALNCO, whether it is best for child or not - easily understood. Concerns that child would consent to decisions even if they don't want to.
- Head teachers massively influence culture of school and that affects how children with ALN's are treated.
- Pwysleisiwyd yr angen am barhad gwasanaethau'r Bwrdd Iechyd yn ystod y trosglwyddiad o Wasanaethau Plant i Wasanaethau Oedolion.
- O safbwynt cyrhaeddiad disgyblion, pwysleisiwyd y dylai targedau fod yn realistig a chyraeddadwy ac nad ydynt, o reidrwydd, yn rhai mesuradwy.
- Nodwyd y bydd oblygiadau cyllidol sylweddol i weithredu'r ddeddfwriaeth a bod angen buddsoddi mewn ymyrraeth gynnar er mwyn osgoi problemau addysgol a chymdeithasol yn hwyrach ymlaen. Crybwyllywd y cynnydd sylweddol yn y nifer o blant ifanc gydag anghenion megis anawsterau iaith a chyfathrebu.
- Cytunwyd, mewn egwyddor, bod un CDU a hwnnw'n cwmpasu'r ystod o gynlluniau cyfredol, i'w ddeisyfu ond amheuwyd ymarferoldeb hynny. Holwyd a fyddai staff Asiantaethau ar gael er mwyn mynychu cyfarfodydd cynllunio ac adolygiadau person ganolog ac a fyddai'r sawl sy'n mynychu â'r awdurdod i wneud penderfyniadau yn enwedig o safbwynt dyrannu adnoddau.
- Mynegwyd pryder ynghylch gallu teuluoedd bregus i fordwyo'r gyfundrefnu newydd gan bwysleisio'r angen am gynhaliaeth annibynnol a diduedd ar gyfer rhieni'n gyffredinol.

- Pwysleisiwyd yr angen am wasanaethau a darpariaethau cyfrwng Cymraeg ar draws Cymru gan gyfeirio at achlysuron o rieni'n cael eu gorfodi i ddewis rhwng darpariaeth anghenion addysgol arbennig a darpariaeth cyfrwng Cymraeg, sy'n annerbyniol.
- Cost cutting before quality and need is not in the best interests of young people in education and we need our young people to reach their full potential with quality support. Additionally education should be a positive experience for all which includes the staff delivering the plans and the ones putting them into action
- I would hope that every child would be given the best chance of a high standard of education that they need to help them access all of the educational needs
And to help them IE what might work for one child might not work for another so this has to be really taken into account if as in our case our daughter has been trying to talk but has limited access to speech and language and because of this this reflects in her grammar in English as she writes as if she is signing in BSL whichever has a knock on affect with her understanding with literature
Deaf children need just as much access to speech and language as they do to BSL this would be a massive improvement on what happens at moment
One last thing is just because someone IE professionals or LEA think that they know what's best for the children they need to Listen to us as parents which has not always happened
- At the moment there is no support/advice in place, unless you are one of the lucky few snap cymru have the time to assist, so things become out of control very quickly when there is a problem. The timescales are abysmal, over a month for an emergency Ed psych assessment to prevent a child being expelled for example. There is no system advertised on what to do if the LA fail to adhere to a current statement which you cannot take to tribunal. There are loads of other examples and issues like this need to be fully covered by the legislation so for every step someone can be held accountable and within a short timeframe. If cases have to go to the tribunal/ombudsmen that is at least a term that child has missed having the services they need
- From my experience, very little support or guidance is given, whatever need your child may have. Luckily the internet is a powerful tool which enables parents to get answers, guidance and help before trying to work with Health Authorities and Schools.

The last two IEP provided for my son, came to nothing. The first was abundant after 4 months apparently because the SEN Teacher left. The

second IEP I don't think it got look at. When I raised this with the new SEN Teacher she assured me all targets were met, even though I could prove they hadn't.

- I do believe that there needs to be some way of bringing health on board and more accountable. But I think before that can happen more capacity has to be built into their service otherwise nothing will change from the 18 month waiting time that there is already to get a child seen by a psychologist and more educational psychologist to support school with the child and their issues.
- I think it's a bad mistake to leave Statementing behind - it's legal clout was the only thing that kept our school and local authority on the right course for our children
- To be honest what I have found is lack of funding. I've been told I have to wait 2 years for the LA to test my son and until then the reports we have on my son the school can only take as a recommendations. The child loses out nobody else. So will these changes have the funding support? 2 years is an unacceptable waiting time
- Snap Cymru are amazing for keeping our fears alleviated, with clear plans on next steps and what to do
- I think more information is needed for children that have health needs. It is not sufficient as it stands.
- Having been informed by Pems CC employees that "statements are being abolished I am very scared for the future of my child's education and wellbeing at school.
- Children with additional learning needs need to be supported in the correct manner and all teachers need to follow a robust framework and to adhere to guidelines. Unfortunately I have had the experience if a teacher who choose not to listen to any advice and decided to overlook my child's need which has had consequences with his self-esteem this type of behaviour from teaching staff is unacceptable
- A case friend or worker is desperately needed for families with children who gave ALN
- I can only describe myself as an utterly frustrated mother of a child who has complex health issues. My child has been out of education at the age of twelve for over six months now and there is no urgency by the authority to get an education for her. I feel this goes against the children's act set by the law of the land
- It is important to realise that all children are from different backgrounds and have different disabilities.
- The whole process of having a child with additional needs is difficult emotionally and practically. I have two children with additional needs. They have attended infant/junior and comprehensive schools. In both cases their needs were minimised by the schools. My youngest child self-

esteem was greatly affected by the lack of provision / understanding provided by the school. More needs to be done so parents understand the transparent process and have access to independent advocates with understanding of the legal process.

- For high schools to be aware that children can become ill with things like ME/CFF and will then need the help of the SEN Service. As this is the biggest cause of absences from school and can be at an important time of their life(GCSE) it is important that they and family get all the help possible as well as advice regarding their education and support for the child so they do not feel they no longer exist. My grandson has been suffering with ME/CFS since November 2011 the school gave no support at all did not even refer him to the educational welfare until I had phoned the educational welfare. The SEN at the school, when he was eventually referred to her in September 2013 said she could not do anything as he was not in school. She did not even write to the WJEC to ensure he was given all the special arrangements he was entitled to. As a result the school disadvantaged him with his English Exam as they did not apply for extra time even though I had asked them to on the advice of Tymes Trust. He ended up with a D where as he had been predicted a B.
- There has to be greater fairness. I have been told that because my child's issues (mental health: attachment disorder re adoption) are not present 100% of the time he cannot have support. If he had a physical disability he would have a significantly greater chance of receiving support. That is completely unfair as his issues are as much as a barrier to learning. I have been told that money has been invested at the strategic level but no-one seems to be able to tell me how success will be measured and I struggle to see how performance as a whole can be measured and the benefit to my child can be measured. Therefore how can a proper evaluation of success or failure be made. I feel the current system varies too much within Wales, by county, school and teacher. The reporting is unreliable also. The school has reported my child to the local authority as being at school action plus but the correspondence I have from school shows him as at school action. If decisions are being based on incorrect data and the view presented is not reality, there is an increased risk that decisions made will be flawed.
- Children need and have a right to an education. In my daughter's case, with sheer determination she is proving that with a little support anything is achievable. A levels and a university education hopefully next year. Who would think this was achievable when It has been a very challenging road, changing colleges, getting funding and support when your age is increasing and location of her specialist facility school is out

of catchment. Luckily she had help to gain funding through SNAP < NDCS and Careers Wales. If my daughter had a plan in the beginning this would not have happened. In the end we had a fight on our hands, had to go to tribunal. But when I got the Education Minister for Wales to understand she was a young woman of 20 who had a lot to give and not a statistic. Things improved and funding was reapplied.

- SNAP has to be much, much better than it is now and has been in the past. The 'relaxed' approach just does not cut it with professionals and policy makers when you need to challenge their wrong decisions about your child's needs.
- The process currently is far too long and children and families are having to wait too long for decisions to be made, appointments to be set up, reports to be written, team meetings to be arranged and the child to be supported fully.
Having been in the process myself with my own child, it is terribly hard and has a huge impact on the child.
My daughter had to wait 4 years to be diagnosed with dyslexia and a 6 years to be diagnosed with ASD. This was due to trainees leaving and new ones picking up the case - therefore starting the processes again. Team meetings taking too long to set up and decisions to be made. Children cannot be observed sufficiently under a half hour visit - visits must be made at home and in the nursery/school to be able to gather a full picture. My daughter has awful memories of primary school due to the way she was treated by teachers who were not trained to deal with or manage ASD or dyslexia.
- We need extra help for preparing for any appeal if we are to get the best for the children.
- Please sort it out urgently. The present system enables families to be dragged to rock bottom.
- Professionals and services don't always communicate effectively. Families after all are not numbers.... They are human.

There is no magic wand in life.... However if there is finally a bill that can truly help to support families like us then that's great. However let's see what the outcomes are and if it's adhered to.

- Most teaching staff have little understanding of SEN in a family capacity.
- It is hard enough being a parent but a parent of a child with special needs is doubly hard and at every turn you face hurdles. Nothing seems to be easy. If you question anything you can be seen as difficult and took over protective. I once had a letter from a consultant which was meant for another consultant but came to me by accident. It said that I was seeking the help of too many professionals. My son has 11 conditions

and this makes you wary of approaching professional. You can't win sometimes....you don't do enough or you do too much.

- There is not enough or sufficient ALN support workers currently in schools to be able to meet current demand and get best out of pupils. The criteria given for a child to have to meet to have IDP means that many children who do have ALN will not qualify for support. Schools do not have enough resources or funding to fully cater for these children on the funding the WG give them to help or give assistance to anyone who generally needs it. There is a middle gap here that needs to be filled to ensure there is funding available for the children who don't quite meet the IDP criteria but who still have significant ALN which need attention and support on a regular basis.
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- The current Bill only includes provision for children within school and formal education settings. What about those children who are too ill to attend school, or those who have been forced to home school due to lack of adequate provision or children whose ALN mean they are better educated in a home setting?
ABA/intensive interaction/Online schools/ institutions/hospitals/ - none of these are taken into account. For some children they will never be able to learn within the school context. What about flexi-schoolers.
- This Bill will enable schools to get rid of expensive or inconvenient pupils and leave them cut adrift with no access to a state education. This is wholly unacceptable. School/FE College is not the right context for all learners. It does not take account the huge variety of ALNs and instead chooses to look at the majority subset only. This totally ignores the needs of a substantial minority completely.
- The new legislation seems to give parents and their young people a major say in their education and care, which is only right. However rights and choice come at a price. There must be funding to support this legislation eg appropriate funding for mainstream schools to support children with complex needs, by employing suitably qualified, experienced additional support workers. At present the situation is very unsatisfactory in some cases, with schools having to meet this specialised provision for children with complex needs out of their ordinary SEN budget, without any extra funding to employ specialised staff. TAs with little or no knowledge of special needs are moved around the school at different times to work with the special child, so there is no consistency or stability of staffing.
- These are our children and for too long people have been allowed to slip between the cracks through funding issues and people who don't do their jobs properly. The affects are devastating when help is not given/or

not properly given, especially at crucial points throughout a person's life. We all need help but society is increasingly geared towards not properly helping/downgrading help for those in society who do not have the capacity to help themselves.

- Parents need to be provided with information on ALL the provisions available within the LA, not just the ONE provision that an unnamed panel member who has never seen their child before, decides on. Give parents all the facts, also make sure everything is known so parents are not repeating information time and time again
- Working directly with schools colleges and LA is an important part of the parents role in ensuring support is implemented at ground level and in agreeing provision in the first instance. However schools and LA should be willing to also work with NHS professionals and allow independent health experts (where waiting times for diagnoses within be NHS delays IDP provision) so that a full holistic understanding of a child's needs are incorporated into an IDP. In addition an independent body should be present throughout the whole process for the parents to ensure that from their knowledge the correct procedures are being followed by all so to reach an efficient and agreeable outcome.
- There needs to be much more transparent information about children's progress through school... the national numeracy and literacy tests are excellent but there need to be initiated much earlier.
- Currently going through the assessment process now with my son who will be 8 in January 2016. My son has learning difficulties, speech development has been slow and assessments for ASD and ADHD at the moment.

It's almost three years so far and still waiting for additional support that he clearly needs. My son had had three exclusions from school and I am worried that this will happen again. Without the extra help he cannot cope.

It's a big worry to myself and the school as my son needs the help and the older he is getting the harder it is going to get. I understand the process is a long road but it seems like it is never ending. Any improvement to the process of diagnosing, assessment and support is very much welcomed with myself.

- It remains unclear as to why the Welsh Government did not seek to adopt the Children and Families Act 2014 which, having received substantial input from a number of influential figures and groups, represents a marked improvement upon previous legislation (Education Act 1996) and indeed the initial White Paper issued by the UK Government. What is most concerning is that Statements of SEN will no longer be created under the new proposals. The 'Individual Development Plan' which will replace statements, will only seek to weaken the

protection offered to those who rely upon it. The removal of legal safeguards will be disastrous, as they are the only checks and balances that exist for ensuring adequate educational provision. Disabled children have the right to an appropriate education, just as typically developing children do.

- Surely, common decency and basic Human Rights for our children should mean that it should never get to the point of legal action, because those working with our children should do everything in their power to be giving them the support and help they need, because it is the right thing to do, even if it is not the easiest thing to manage! AND if the school cannot meet those needs as stated, they should have a clear route to discuss this with all agencies involved when necessary, to resolve the situation and find a route that works for them whilst still meeting a child's needs.
- Whichever system is put in place, this doesn't seem to tackle one very key issue which I believe is having the biggest impact on making it a battle to get appropriate provision for my son. That is the availability of funding for addressing the needs of these children and young people. I think that however the law is worded, the system has to be funded properly in order to make a real difference to their life chances. Law in this country is often open to a degree of interpretation and without proper funding the interpretation of it by the professionals involved is going to be in whatever way that allows money to be saved. Not providing resources now means society is setting these children and young people up to fail and be dependent in later life. In addition, there is a seemingly target driven approach to education where schools getting a high percentage of students over a certain benchmark in tests and exams to be considered "good" schools appears to be the be all and end all. Therefore I do wonder how much schools and LEAs really want to put in to dealing with students who are unlikely to be able to meet those benchmarks, even if that funding and resources improves the outcomes for those individuals. Looking at my own son, I find the whole situation hugely worrying.
- Please ensure THAT CHILDREN CURRENTLY AWAITING DIAGNOSIS OR WHO MAY HAVE BEEN MISDIAGNOSED ARE STILL GIVEN THE SAME RIGHTS AS CHILDREN WITH A DIAGNOSIS AND A STATEMENT SHOULD NOT BE ONLY GIVEN IF YOU HAVE A DIAGNOSIS PARENTS/CARERS KNOW WHEN SOMETHING IS DIFFERENT ABOUT THEIR CHILD WE HAVE TO LIVE WITH THE SITUATION 24 HOURS A DAY AND OUR FEELINGS AND OPINIONS SHOULD NOT BE IGNORED IF A CHILD HAS NOT BEEN STATEMENTED AND CAHMS NEEDS TO HAVE SUFFICIENT FUNDING TO HELP CHILDREN AND THEIR FAMILIES THROUGH WHAT IS A DIFFICULT AND DEMANDING TIME.

- It would appear that there has been little consultation between services and people whose lives this Law will have an effect upon. The only public meeting brought to my notice was undertaken by SNAP when they held meetings to explain the intention of changes to the present statutory process.
- **I am a teacher, SENCo and a parent of a child with complex difficulties.** I have the unique perspective from various angles and have personally experienced many of the current processes over the last 14 years. I welcome any changes that put the child first. It concerns me that inclusion will become more difficult to achieve as the work involved in creating the needed paperwork will fall on the school not the LA. It concerns me that the workload of a Senco would be unmanageable as most are full time teachers and this could cause an unconscious negative feeling of having these children at their school due to the workload that they bring. Would it now be harder for parents to get the school to place them on IDP in the first place? There needs to be some sort of graduation. Even if it is just a 'concern list'. Also lot of parents are not capable of seeking the right support and if a child is unable to fully understand their needs who will look over it then? Also it has always seemed to be those who shouted the loudest got the most. This culture needs to stop and difficult unreasonable and demanding parents need to be told honestly about available funding as it is not a bottomless pot of money and resources need to be shared fairly.