family ADVOCACY

Institute for Family Advocacy & Leadership Development Assoc. Inc.

A New South Wales association concerned with the rights and interests of people who have developmental disability

The Hon. Natasha Maclaren-Jones MLC
Deputy Chair
Portfolio Committee No. 3 - Education
Parliament House
SYDNEY NSW 2000

Monday 1 May, 2017

To the Hon. Natasha Maclaren-Jones and members of the Committee,

Re: Question on notice - examples of the type of modifications which parents have requested and which schools have refused

I attach a spreadsheet detailing examples of the modifications that parents have requested and which schools have refused or not actioned for your attention. If a parent has provided an example where an adjustment has been accommodated well, we have also included this.

We sent the question on notice to families of school age children connected with our organisation, and parents responded via phone or email. Thus the description of the adjustment requested and the school response are sometimes in the first person, as written by parents themselves, though we may have at times edited for clarity or length. The meaning of the responses has not been changed. The examples have been de-identified and pseudonyms used, however, Family Advocacy has retained an original copy with identifying details. If the committee have further questions about a particular instance, we can facilitate this.

In response to the supplementary question, Family Advocacy receives roughly 50 per cent of its funding from the Commonwealth Government's National Disability Advocacy Program, and another 50 per cent from the NSW Government, largely from the Department of Ageing, Disability and Home Care (ADHC). I attach our 2015-16 Annual Report, which includes a breakdown of funding sources on page 48. While Family Advocacy, and advocacy generally, is not a 'disability service' in the traditional sense, this ADHC funding is included in disability services funding which will be transferred to the Commonwealth to fund the NDIS. Advocacy funding will not be kept aside for advocacy at the federal level, and thus Family Advocacy is very concerned about the loss of advocacy services for a very vulnerable group. The current inquiry is a perfect example of the need for advocacy for people with disability in state service provision.

Kind regards,

Dr Meg Clement-Couzner

Senior Systemic Advocate

Age/year level and setting if known	**Adjustment requested**	**School response**
Key	**One modification per row, some families gave multiple examples and therefore have multiple rows allocated. Change of row colour = new family.**	
Yr 4, regular class	Parents requested an assistive technology assessment from the Department of Education. The assessment recommended an iPad, as Noah (child) has trouble writing. The school refused to fund it until Marion (parent) "asked to speak to someone in the department". Software on iPad was then received ($350); however, family had to go back through process of application, teacher had to write a learning and teaching 'case' which was then rejected and had to be redone. Had to have the Department of Education IT department install the apps.	Principal wanted the parents to go through a private provider even though the Department of Education has the expertise. Principal told parents would take a year with Department. When they finally got her to do the forms it only took until the next term and was excellent. iPad purchase took nine months.
Yr 4, regular class	Requested modified report to individual education plan rather than to standard key learning iniatives. The parent can not go through the report with her son because everything says 'poor'.	Request was refused. Parent has sense that the principal's attitude is "this is what happens in mainstream and if he can't cope should go back to the special needs unit".
Yr 4, regular class	Behaviour management modification. Standard class practice is that if student's behaviour is bad they have to go to the reflection room to hand write how their behaviour has impacted others. Noah cannot write without support, it would take him a long time and he would need a computer, none of which is available.	The school refuses to a) put in place an option he can actually do or b) let him do the reflection when he has had time to process because "he's in mainstream and this is what happens." They say it does not matter if it is an effective exercise for Noah, this is how the school executive team can see what's happening and have it properly documented.
Yr 1	Request for therapies in school. Eg speech therapy.	Told children need to do this after school.
Yr 2	Following the adjustments being allowed last year, requests were made for: a visual timetable, ensuring that noise reducing headphones are at all times available, sitting straight on to classroom board rather than side on, a quiet area set up to retreat into when overstimulated.	No response and no action on the visual timetable, despite documentation showing the school has to request it from psychologist and occupational therapist. The teacher has told my daughter that she is "not allowed" to have headphones on some occasions and brings them to others, no pattern discernible which is difficult as my daughter needs them and she can't understand when she is or is no allowed. A quiet area is set up, but my daughter hasn't been allowed to feel safe there so she doesn't seek the area when she needs to self regulate. Sitting straight on to classroom board rather than side on has been ignored and daughter is currently sitting at far end of classroom side on.
Yr 3	Requested aide for classroom.	I don't want the aide always working with my child, but be there to benefit the whole class and be present in the room if needed to help my child with autism. Apparently that modification is too much for any catholic primary school in my area. As a result, my son had to be in a special school for kindergarten to year 2. He doesn't like being with all the other autism spectrum disorder kids due to their noise and unexpected behaviours. He has 2.75 more years in primary school and I feel he has been denied access to a mainstream class, but it's hard to keep battling this on top of everything else I do.
Yr 4	I had asked for photos to be taken and emailed to show me a bit about what my child was doing as an attempt to enhance communication.	Didn't occur.
Yr 4	Have been trying to get a learning support plan established. At these meetings, we asked to see examples of some of the work our child was doing. We were repeatedly told that it was too difficult to provide this. Eventually we were finally given a few examples of what one of the teachers was doing at that time with the class. We were quite bamboozled by it as we ourselves did not understand what was required to do this work let alone how Ros (our child) could do it. At the end of that year all of Ros' work came home as it does for all students. It was then that we could finally see how difficult it had been for her and how much education she had missed out on due to lack of adequate classroom adjustments when compared to the work she used to do at her previous school. On one maths sheet, she had attempted all the questions and every answer was marked by the teacher with a cross.	School did not seem to consider feedback, parents eventually pulled child from school.
Yr 3, regular class	A communication book to pass information about my child's health and the impact it might have on her learning at times.	The school said, "if we allow it for your child we would need to allow it for every child and that wouldn't be manageable." Information, about important issues that impact my child (such as bouts of sleep apnea) was not passed on to the teacher. As a result my child was being perceived as stubborn and uncooperative when she might actually have needed some quiet time and some rest to alleviate the effect of sleep apnea.
Yr 3, regular class	I repeatedly ask for a daily visual timetable on my child's desk as she struggles with transitioning from one activity to another.	None, it just never happened that year. As a result my child just kept being uncooperative and oppositional.
Yr 3, regular class	That my child be given a simplified shorter spelling list to practice at home and be tested on weekly alongside all the other students in her class. We agreed on 5 simple words per week (instead of 20 more complex words that other students get). The teacher would choose the words according to themes that would be covered in class during that week.	The teacher provided the list which we practiced at home. Those words were included in the spelling test which all students undertook every Monday. As a result my child's writing skills improved immensely. Writing has become her favourite activity and her academic strength.
	On many occasions, I have raised my concerns about the literacy programs being implemented, as well as asking for adjustments to be made to accommodate my son's learning difficulty. I have felt a moral obligation to do so as I firmly believe that every child would benefit from these adjustments, not just my son. Many of these adjustments are basic and no parents should have to specifically ask for them, such as sitting up straight.	I have been ignored and told by management, "we appreciate your passion, but these are just your opinions," and "we can't give every parent what they want." The ignorance displayed by teachers, school boards and management as to what research indicates is best practice in education is alarming.
	Actively teach handwriting. Handwriting is the first subskill of reading as it links the spoken sound to the written symbol. There is a large body of research that supports handwriting. When we write by hand, we write more and it is of higher quality. It is unusual to see cursive handwriting taught or used by students anymore, even though it is mandated by the Department of Education English curriculum. I would also caution that copying from a handwriting text book (developed by publishing companies whose primary existence is to make a profit) is not teaching handwriting. Cursive writing calls upon many areas of the brain; it fosters neural connections between the right and left hemispheres. This would adversely affect his learning as volumes of research indicate that learning to write by hand plays a key role in developing literacy.	The principal of my son's school once announced to the whole school community that handwriting was going the way of the "Dodo bird" (her words) due to technology.
	Have children seated directly facing the board or teacher during direct instruction. Twisting and turning the body to see information is very confusing for children who have difficulties with directionality and laterality.	
	Provide students with a slanted board or slanted desk. Dr Darrell Boyd Harmon conducted extensive research into slanted boards. The research demonstrates that using a slanted board for writing and reading reduces visual stress. Promotes fine and visual motor skills, promotes better handwriting, better posture and better visual tracking for reading.	It is only this year that my son finally has been allowed a slanted board on his desk at school.
	Provide lined paper. One of the subskills of reading is feature recognition; the ability to distinguish between vertical, diagonal and horizontal lines and curves. It is difficult to distinguish between short and tall letter part without a reference point, being lined paper.	
Yr 11	Allow John to leave the classroom with a school learning support officer (SLSO) whenever his anxiety levels were raised. This was to avoid an undesirable behaviour occurring. It was recommended by his psychologist after she had spent time observing John in the classroom.	Would not allow it. Said that a SLSO could not be alone with a student at any time. Eventually started removing the whole class and leaving John in the room either alone or with a teacher. The SLSO would take the rest of the students out.
Yr 11	Provide John with a SLSO until a learnt behaviour of throwing puzzle pieces in the air (which he had learnt at school) came under control.	School response: Would not provide as "SLSO's are allocated according to available school and Department of Education resources and with the needs of all students in mind. At present there are no plans to employ additional SLSO staff."
Yr 11	That John be allowed to touch staff appropriately and vice-versa. Requested that praise be given to John in the form of high-fives. Requested that staff gently touch John's arm or back to reassure him when his anxiety levels were rising.	This was requested on many occasions. Various responses were given including, no touch policy within Department of Education. I looked everywhere to try and find this policy and could not find one. If we give hi-fives to John then other students would expect it.
Yr 11	Idividual Education Plan be prepared for John at the beginning of the year, by Week 5.	Planning meeting held in Week 5 but no individual education plan was ever finalised.
Yr 11	Consideration or plan for work experience options for John. If John was not suited to learning within a classroom setting then we thought to try work experience options.	Form given to us to complete regarding work experience readiness. School never requested the form be returned. The school said they would organise a meeting to discuss but this kept getting postponed.

Yr 11	Request to see what resources were available in a Autism Support Unit that could be brought back to his school to assist John in his current setting. This request was made after numerous requests from the school to transfer John to this particular support unit which were refused.	Meeting arranged at school with Autism Support Unit. No visit made to classroom to see what resources were available. Parents told they needed to request to transfer John or he would be expelled.
Yr 11	Request that Head Teacher of Welfare form part of John's Learning and Support team. This person within the school had built a good rapport with John.	Denied. The principal had other projects for this person to work on.
Yr 2	Access to a sensory corner.	School provided after lots of pushing.
Yr 2	Asked her teacher to start using icon pictures for the program for the day	The teacher put his hand in the face of the mother and said he did not need to know any more because "I have worked with professionals." The teacher for Lili would say yes to most requests during meetings with the principal and Department of Education were present, but would not act on them.
Yr 2	Lili had become resistant to attending school. Her Mum got her to school for a whole term using the motivation of a frog pond, much valued by Lili, which was built on the school grounds.	This was allowed but other kids from her class were not allowed to go to the pond, further isolating Lili.
Yr 2	During meetings, the school would say it was fine for Lili to use sensory objects (such as fiddle toys).	In the classroom it was discouraged. School teachers also said you can not fiddle and listen at the same time.
Yr 11	When my son was in a Year1/Year 2 composite class in the segregated 'Support Unit' of our local public school, I asked several times if he could be in mainstream classes with typically developing students. My son has Down Syndrome and is an observational, visual learner. Since he was placed in the unit where all the students had learning difficulties and unusual behaviours he was starting to copy their ways, such as hand flapping which he's never done before.	The school principal and school counsellor both refused my express wishes for my son to be in mainstream classes. They told me that my son would need a teacher's aide to support him in a regular class room. All the school's support funds were allocated to the segregated Support Unit and they had no funds to employ more staff to support students outside this unit. I then began in earnest to seek a school that would include my son in all classrooms. No other public or Catholic school in our area would enrol him and he was refused from four of the five independent Christian schools in our area. All the independent schools cited inadequate funding as their reason for refusal and told me the public schools get far more support funds. I enrolled my son in Year 3 at the only school in our area that welcomed my son. This school has no segratated learning and provided in-class support for the teachers who have students with extra support needs in their regular classroom. My son in now in Year 10 having had many happy years at school. He LOVES going to school and has some close friends there.
	Request that an independent speech therapist be allowed to come to the public school to give my son with a disability speech therapy. Note that my son was required to go to many, many doctor's appointments, and getting him to another out of school appointment was impossible to maintain.	The school did not allow independent practitioners into the school. I have since become aware that the new principal of the same school now allows this to happen for children with disability, which I think is very good. The decision appears to rest with individuals in each school, which appears inconsistent.
Yr 8, regular class	Children returning to school with complex needs do have to jump through a lot of hoops. Our son Tim has severe cerebral palsy, uses a wheelchair and is peg fed and recently had deep brain stimulation . He has an implanted battery box which controls unnecessary movements.	Tim who was ready to return to school in late September was still waiting for all aids to be trained in December 2016 before he could return to school. Overall ours is a good news story, but the message really is that a huge burden is put on parents to organise the required adjustments through Childrens hospital, nurses training, etc on top of the depts. Training course 'Health Care Procedures' had to be undertaken by Tim's SLSOs. As the course was only available three or four times a year and Tim had 8 or so SLSOs needing to all be trained and certified as competent. He had been in Children's hospital from February to July and nearly was unable to go to school till mid-December because a course for an SLSO was not available. The school did a huge job in establishing procedures for peg feeding, but it was a fairly huge pressure on me as a mum to get doctor's certificates and be present at the school for several months.
Yr 8, support unit	Requested access to regular school resources while son in the support unit (e.g. readers, excursions, homework, welfare and discipline policies).	
Yr 2, regular class	Mum suggested a visual timer for daughter who gets anxious if feels she has not completed the work. Also struggles to stay on task. The timer can alleviate the issues at transition times in class or between tasks.	No acknowledgement of importance of this so no changes occurred.
13 yrs, regular class	School has purchased speech to text technology to assist student.	No staff have been trained and so program is not being used. There seems no intention of this changing.
Primary school	Has asked school to allow her daughter to use green coloured paper as this helps her to see the words on the page. This has also been verified by her doctor as a useful adjustment.	School will not provide different coloured paper.
Yr 3	Parent asked school to help her son be more engaged with school work.	The suggestion by the educator was to keep him in at lunch for extra time.
Yr 2 regular class	Requested an Auslan interpreter.	We do have someone working in this position but they are not qualified by the National Accreditation Authority for Translators and Interpreters (NAATI). This has been a constant battle with the school.
Yr 2 regular class	Trialling a pass-around microphone such as the Phonak Dynamic.	This has not been actioned still to this day.
Yr 2 regular class	Seating arrangements that enhance Oscar's ability to hear in the classroom and see both the Auslan interpreter and speaker at the same time.	Initially Oscar was seated to the back as the "interpreter" was perceived as distracting but after heavy advocating from me this was changed so he now sits to the front. The interpreter was also standing on the opposite side of the classroom to the speaker and was only being used when they felt he needed it. This was rectified after advocating and a phone call to the Deaf Society and the Royal Institute for Deaf and Blind Children (RIDBC). Assemblies are still an issue as the interpreter is constantly being obstructed by teachers and other students.
Yr 2 regular class	Minimising background noise to a level specified in the Australian standard ANZS:2000	Initial refusal after request in 2013 (child started school 2014). The principal's words were, "I refuse to make adjustments to the classroom that i feel are cosmetic," "no one is going to come into my school and tell me what I can or can't do," "even if I agreed to put in these adjustments its likely that it wouldn't happen for at least 18 months," "we have kids in wheelchairs in this school that don't have a ramp to get up on stage an accept an award so why do you think your son deserves an adjustment more than these kids," "think yourself lucky that you go to this school as I know principals that really discriminate against their kids, for example X and X public schools have fully deaf children without any support or access to sign language so you should think yourself lucky." After a ministerial complaint the principal finally agreed to make the acoustic adjustments but this didn't happen till Term 1 in 2016. The principal said "I had Oscar's room checked by acoustic specialists and his room would of had to be the worst room for acoustics in our school," and I (mother) said "thank you for agreeing to making this adjustment." Principal replied that he "didn't do it for you or your son but all the other kids in the school that might benefit". The room Oscar is currently in has acoustic adjustments but another area that he works in does not. We were told last year that this would be fixed and it has not.
Yr 2 regular class	Enhancing speech reading conditions, for example avoiding the hand covering the mouth, not turning your back when speaking etc.	This has been achieved by a very proactive teacher. Initially this wasn't the case but changed after our advocacy in 2015.
Yr 2 regular class	Repetition and clarification of communication.	This has started to happen after our human rights complaint but wasn't happening prior to that time.
Yr 2 regular class	Reducing visual distractions, such as sitting near a busy area of the classroom or thoroughfare.	This has been happening due to the efforts of our proactive teacher. Initially this wasn't the case but changed after our advocacy in 2015.
Yr 2 regular class	Frequently check if Oscar is understanding the content eg asking Oscar to repeat what he heard.	This strategy has been recommended on numerous occasions but has only started to be used since our human rights complaint.
Yr 2 regular class	Supplement verbal instruction with visual cues and materials.	This does not happen. The classroom teacher does use a visual schedule with the whole class but that would be the extent of the visual support. We work with Oscar at home with visual supports that give him meaning and understanding of what he is learning. I have previously asked the school to follow suit but have always been met with resistance. I have been told that they can't fit these supports into the classroom and that they don't have the time to provide them. I have offered to make them for the school if they would let me know the areas that he needs more support. The school has never taken me up on that offer.
Yr 2 regular class	Buddy system for notes, extra explanation and direction.	Has never been actioned.

Yr 2 regular class	Captioning for television, videos and movies.	Initially this did not happen but after advocating for Oscar in 2015, the classroom teacher now uses captioning in the classroom. Unfortunately this doesn't extend to the rest of the school and Oscar is constantly discriminated against. The school has regular movie nights and they have informed us that they can not provide access for Oscar on that scale so unfortunately he can not come. Sometimes the school has movies throughout the day and we have been told that they can not provide access for Oscar so I can pick him up earlier or he can watch it with the SLSO in the classroom.
Yr 2 regular class	Regular down time/breaks from listening throughout the day. Oscar should chose whether he removes his devices for short periods.	I have advocated for this from the beginning but unfortunately due to lack of understanding this does not happen. This has been recommended since the 2013 reports as Oscar would be easily fatigued by the effort it takes him to try and hear what is being said and background noise makes this even more difficult.
Yr 2 regular class	Remind Oscar to go to the toilet.	Sometimes the school "toilet times" Oscar and other times they forget. I have spoken to the school about this (when Oscar has had an accident) and they have admitted that they forgot to toilet time him on that day.
Yr 2 regular class	Strategies to develop handwriting skills.	This has been an ongoing battle and the school has finally moved Oscar onto keyboards. We are now working on the handwriting strategies at home and progressing really well. I was getting frustrated with the school as the SLSO was note taking most of Oscars work over the last couple of years and I feel that this negatively impacted his ability to learn this skill.
Yr 4, regular class	The adjustment we asked for (and the psychometric test recommended) was behaviour support. The school and CEO said this would mean having an aide in the classroom.	The school and CEO advised this would only be possible if we funded the aide ourselves, including leave for the aide and allowing the aide to be available for other children. We felt we had no choice but to walk away.
Primary school	Mother suggested having a visual timetable so her son understands library is on that day and isn't surprised by that, as he gets anxious everytime his class goes to library.	School have not tried this idea.
common example, both levels and settings	Parents wanting to be able to communicate effectively with school through a booklet or email system. This is to try and assist with class management and understanding of student.	School not wanting to do this task and so no daily communication occurs. This can cause further issues as the student is not understood and often poor behaviour can occur that may have been mitigated by better communication.
common example, both levels and settings	Parents asking for reporting systems that indicate how the student is going against their personal set goals rather than against the stage outcomes.	Do not want to change any part of the standardised reporting so it can be disempowering for the student and doesn't reflect any improvements and good outcomes that have been gained.