

**INQUIRY INTO STUDENTS WITH A DISABILITY OR
SPECIAL NEEDS IN NEW SOUTH WALES SCHOOLS**

Organisation: XXYY Australia
Date received: 25 November 2016

Inquiry into the provision of education to students with a disability or special needs in government and non-government schools in New South Wales

Please accept this submission on behalf of the Australian XYY Families. We seek to maintain anonymity of my name and personal contact details.

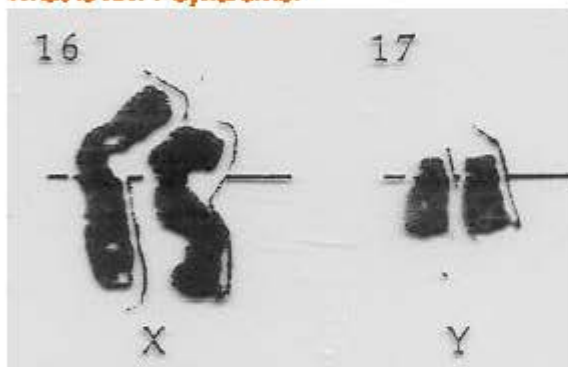
This submission will address the following Terms of Reference as noted below:

Terms of Reference 1 (our request):

- **Equitable access to resources for students with a disability or special needs in regional and metropolitan areas.**
- **Complaint and review mechanisms within the school systems in New South Wales for parents and carers – example provided**

Background:

What is XYY Syndrome?



48, XYY is a sex chromosome variation that affects one in every 17,000 boys who are born.[1] XYY Syndrome is the name attached to the cluster of symptoms that arise as a result of the 48, XYY chromosome pattern.

48, XYY is one of several types of sex chromosome variations, including those that are considered as variants of Klinefelter Syndrome, 47 XXY and XXXY, XXXXY, XY/XXY and another syndrome called XYY, all of which affect males. Similar female syndromes include Turner Syndrome (XO) and several variations with added X's. There are important differences, between boys and men with 47,XXY and those with 48,XYY. [1] The incidence of 48,XYY syndrome was originally estimated at 1/50,000 (Sorensen et al., 1978), but a recent report found the 48,XYY karyotype in 1/17,000 males in a newborn screening (Nielsen et al., 1991).

Characteristics of XYY Syndrome

XYY is often mistaken for other syndromes. The most common symptoms and characteristics that would be noticeable by parents, teachers, medical professionals and other treatment providers are:

- Developmental delays
- Speech impairment or delay
- Tall, considering family history
- Behaviour outbursts & mood swings
- Learning disabilities
- Intellectual impairment
- ADD or ADHD symptoms
- Autism, autism spectrum, PDD-NOS
- Scoliosis

- Clinodactyly (Curved-in pinky fingers)
- Low muscle tone
- Flat feet/club feet
- Sterility
- Delayed sexual development
- Undescended testes
- Low or no testosterone
- Dental problems
- Leg ulcers
- Heart defects (ie VSD)

<http://xxyysyndrome.org/main/xxyy-syndrome/>

Education

Teachers are an extremely important piece of the XXY puzzle. We request the availability/access of/to teachers who are made aware of XXY chromosomal children's requirements and characteristics.

Males with XXY are visual learners. They often hide in small places (under the desk, for example) because of sensory overload. Because of hand tremors, they may have significant difficulties with writing. Behaviour outbursts may also happen.

Speech, Physical and Occupational Therapists

Therapists, especially speech therapists, are often the first to see a male with XXY Syndrome since speech delay is one of the first symptoms to become apparent. Some parents have found the use of sign language when a child is young seems to reduce frustration considerably. Because of low muscle tone, males with XXY Syndrome need strengthening exercises for all muscles. A plan that includes all three therapies is the best possible assistance that can be given to a male with XXY Syndrome at an early age. Occupational therapy is very valuable and if it can be done in conjunction with some training for the classroom teacher, it is most beneficial.

<http://xxyysyndrome.org/main/xxyy-syndrome/information-for-professionals/>

XXY Males learning ability is variable in all the affected males mostly based on their medical conditions and history with some known to have finished degrees and many in the workforce worldwide. There is 15 known cases currently in Australia.

Equitable access: Teaching and Learning

Teaching criteria for the IO and IM classes – the expected end results produced and outcome expected of students is not of a high-quality standard. 21st Century learning aims to prepare students for the future in an integrated and motivational manner to achieve personal academic goals that will equip them for the years beyond school and enter young adulthood.

We already have examples and can highlight children whose experiences does not really show any growth either intellectual or personal.

Currently students are trained in basic life skills that will only equip them for inconsequential and menial employment appears and that appears to be the standardised approach of education in our experience, for example, the results demonstrated in the community after graduating high school for an IO student equates to poorly paid jobs with reliance on government benefits and in receipt of as little as \$1.00 per working hour. We believe this in spite of the capability of some of XXY children who are more capable than what is expected within the status quo.

The enrolment of students at IO level it seems does not allow that exposure or training that would assist students to move forward in levels to achieve higher grades to bring them to levels of IM. Efforts of the teaching faculty, we believe, fall short of achieving a satisfactory level of education for students

who fall marginally between the IO and the IM level are provided exposure to the level of education that will allow them a reasonable standing in society or in the work place due to lower levels of standardised education at the IO level.

There are no set benchmarks, education and training facilities available within the system to allow the re-evaluation of students for them to move to higher levels of education. It must be appreciated that each student in IO and IM have differing capabilities pending types of disabilities and not all students can adapt to the same type of education and training. While we understand a lack of resources, we believe substantial growth can be achieved by getting better educated teachers.

In an IO Class, most students are nonverbal with moderate to severe level of intellectual disability and require continuous assistance from the one teacher and the aide.

This disrupts the learning environment for the remaining marginal students that have mild intellectual disability, however with a greater potential for growth and ability to engage independently within our society. There is a clear need for a level of support who, if given the resources will change the lives of a lot of our marginal XXYY children and produce greater independence for the future.

Therefore this does justify IO/IM class establishment for students whose abilities have enabled them to progress, whose potential can be honed for the betterment of personal and educational outcomes, producing life skills which focusses on more the very basics.

Presently it is noted that a student in a disability class can share the same teacher for four years with the same set of students until they leave school or graduate. This is an unhealthy recipe for accountability to judge the progress of the student as there are no tests or exams. Year 12 students are in the same class as Year 9 students. This may not auger well in the long term for the student or the teacher as they may have burnouts. **We request that every level needs to have a specialised teacher as these are the students who need the most help and support.**

The efforts of the same teacher are distributed amongst 9 to 10 students. From year to year there are additional needs that need to be addressed, such as behaviour, autism, health, sensory that impact on the dynamics of a special needs classroom adding to further demands on the classroom teacher; hence the request for specifically trained teaching personnel for each year of growth.

The Mainstream classes might see a composite class, e.g. 9/10 and this is still difficult for a mainstream teacher to manage. Class size could be made flexible depending on the needs of the students; this, of course, requires additional resources and funding; which we request for a longer term independence of our XXYY affected citizens.

We recommend that students are not treated only as children who require day-care type support to go through the day; rather, access to trained teachers who are able to provide tactile and real education to the children based on their year level (year 9 or 10) and capabilities / characteristics.

Rotation of staffing per class is an absolute must due to being a very small and isolated unit in major schools where power remain with only a few, namely the class teacher and the Head Teacher. With little accountability and transparency based on students whose abilities are different, it is very important that when selecting a support teacher, an endorsed panel is invited to participate in the selection in every opening of teacher position.

When accepting new students into an IO class, the teacher requires refresher training and a thorough understanding of the students' behaviour and needs to ensure a least disruptive class room environment. Having the same teacher, who must cater for all the different needs and years/stages of education plus the ongoing training for the advancement of the 21st Century Learning is a precursor to 'burn out' exacerbating the already difficult challenges needed to be addressed daily.

The teacher should be conversant in all stages and development of the students' needs and therefore the minimal staffing ration is questionable. The teacher will have an overall knowledge on how to accommodate the students and assist them in finishing off their senior high school year of education whilst meeting the "required" curriculum for special needs class. The students are not encouraged to be challenged to their potential due to the inability of the staff to provide resources and the limited

availability of staff and the education system. Ongoing enhancement of the teaching staff for each year/stage will benefit the future outcome of the education system.

These are students who need to be able to access speech pathologist while in school. Most of them graduate not being able to hold proper conversation and never have had any access to therapies such as Speech, OT or Physio. There are times when families cannot afford these services due to shortage of money or time and universal services are extremely limited and difficult to access. The educative environment could be integrated with the health system to support such students across government as a possibility for consideration.

In relation to 21st Century Learning, these students are not on par with the mainstream students and may not have the proper knowledge on how to go on to the websites and use the computer as a tool for ordering items and paying bills rather than a gaming machine.

They need to be given more resources and access to IT. There is no comparison with the mainstream students who these days are learning coding in Kindergarten and Stage 1.

Ability and Evaluation for Progress

The evaluation process for each special need student must be supported via frequent testing and ILPs set out. There must be more emphasis on Learning and engaging these students, giving them opportunities to mingle with the mainstream students as much as possible through organised activities that promote group learning and socialising. It is therefore important that more discretion is required for each student to be provided the appropriate level of support and education so that they get more out of the education system than a stereotype syllabus which is standard for each.

Whilst the NDIS is taking shape and form, similar resources need to be organised for education for these special children at the schools with focus on transitions to post-secondary education or training at University, TAFE, or with a registered training organisation.

The current method segregates the special needs class against the mainstream. The special needs students do have many more requirements compared to the mainstream students and they need to be given all the chances available to encourage efforts to achieve that any other person would. Labelling them as "disabled" and expecting them to follow a set path such as the well-known but deficient Life skills program will not help their future or the structure of social standing.

Work experience begins from Year 9 and takes a day of learning away from the school environment. It is a good thing, however looking at the 2 weekly timetables where there is a day out for living skills does not leave much room for actual academic study. The hours of actual study contact is very limited, giving the students and teacher limited time to engage in the academic side of the living skills. This part of education provides mind training and enhances their ability to become wise and independent once they come out of school giving them higher self-esteem and knowledge of the world around them.

One must note that the work experience afforded to IO students is mostly among people who are adults that have a moderate to severe disability of some kind. The mind set being created for every individual accessing this training leans towards the feeling that this is the real job that they may end up with. It is important that the education system goes beyond this branding of jobs and stunting their abilities and builds aspirations and life goals to achieve more.

Once these students graduate the work force life is not made at all easy or appealing for them. The pay is a meagre \$1 an hour to \$7 an hour (if you are a TAFE graduate). Therefore, their capabilities need to be expanded with the intention of being able to hold higher status jobs with more options and less discrimination. The education system needs to be rewritten and designed in such a way to accommodate current standard of living and accepted lifestyles in the community.

The teaching staffs need to have the additional training to recognise the potential of each student and their strengths that can provide support to build upon. This pathway should be built on partnership

between teaching staff and parents with lots of feedback, meetings, ILPs and continuous appraisals giving the students self-pride and building their self-esteem.

The representatives and case holders of the Education Department need to be making frequent trips to the school and checking on the progress of the students and evaluating their current situation with school staff and parents. The school and/or the Education Department need to work with parents and introduce the NDIS. NDIS needs to be linked to furtherance of education and progress of students to bring out their optimum level of proficiency.

The department does the placement for the students and does not ever do an audit to appraise the status of education and the level of support provided.

Parents should have access to an independent contact; not part of school staffing to discuss issues or grievances that may impact their XXYY affected child's school life. Now, in our experience the Head of Support has all the power and communication can be made difficult at best. This also raises the issue of transparency because it may have an impact on the practices of the Head Teacher directly.

It is very easy to dismiss students with disability as a non-performing unit where teachers have the sole discretion at their disposal to either criticise or promote the student. These students have every right to be proud of their school and the school should reciprocate this feeling towards them.

Teaching and Learning spaces

Teaching and learning spaces should be of a sufficient size to support a number of different teaching and learning activities. It should support additional space for students with mobility aids. Break out/support spaces for teachers and other professional to work with individual students or small groups. This supports the relationship between student and teacher and provides a quiet space to calm down and re-focus when needed. Close proximity of break out spaces to main learning spaces for easy accessibility to reduce distress during transit and for students to remain connected to the class. (Due to lack of classroom space, there have been known cases of Autistic students moved outside the classroom door into the corridor.) Heating, lighting, ventilation and acoustics need to be considered too.

It is very hard and demanding for a person with disability to remain seated at all times at a desk in a small room which harbours these students for six hours a day. The students spend majority of the day in the same classroom as they are not moved around for every subject. Space for movement for these students are important to have them more active. Classrooms have to be larger for these kids and set up in ways to encourage comfort and space.

There has to be storage space for these students to put their personal items as it is very difficult for this students to organise themselves in a daily basis.

XXYY Syndrome and education:

Talking to parents and adult XXYY boys, the meetings between teachers and parents have always come up with a bleak attitude by the teachers and counsellors in terms of what should be expected thus from the support student. This does reflect on the current education system where teachers need to be trained to concentrate on developing the student's abilities rather than following an assumed result which could be totally different based on the school's ability to harness the potential of the student.

Parents of XXYY students have also noted that the education system followed by teachers and structures of learning process and the hierarchy of teachers are the cause of complacency in the performance of teachers which is reflected through the students.

It is important for the classrooms to be designed to accommodate these students as they have sensory overloads. Students having similar behaviour or erratic behaviour patterns need to be placed together in a different class with additional resources to cope. Classrooms need to be large enough so that the students having their outbursts won't have impact on the other students in the class. The ability of

students who have mild behaviour patterns to perform is distorted whilst in the continuous company of erratic behaviour students.

There is a beautiful world out there for the "normal" people and the disabled unfortunately have to be placed into a system that "seems to work" according to a set pattern that might have worked for a few students and not necessarily for the others.

An evaluation of the provision of education to special needs students is totally overdue and major reforms are needed.

The Education department needs do studies and surveys on the outcome of students graduated from Support Schools and work out the discrepancies and the shortcomings. Teacher expectations of students with learning disability are low and systems in place in the education system seem to aim low and the use of much generalised pattern of "one fits all" study curriculum seems to be the current study technique. Teachers still teach the same content to the whole class regardless of the ability levels within that class with meagre resources. This is regardless of the Disability Discrimination Act 1992, which promotes equal opportunity and access to education. In a support environment it is very essential that the courses are designed based on each students requirements and learning capability rather than teachers fighting fires to keep a diverse class of various students with behaviour issues in control.

Students can end up thoroughly discouraged, with very poor self-esteem, continued and often subtle, underhanded discrimination by other children and unmotivated to apply effort. It can take a specialist educator and other professionals help to reverse these effects. It wastes much time to have that child staying in an IO Class disengaged, continually faced each day with non-academic work that deters their progress and not cater for their level of needs.

Decisions are not collaborative:

Some schools only include their special educators on their Learning and Support Teams. Meetings and decision-making may only include the Head of Support & the school counsellor and parent(s) with no input from the Principal or Deputies. The teacher is hardly ever present in these meetings except during the parent/teacher nights twice a year. The engaging of parents in the development of the students in all facets learning processes is an absolute must conjointly with the ongoing planning and directions at school. These meetings should be held at least twice every term with follow-up.

The options for school placements for IO students is determined by a panel and is reviewable, however for all intention purposes there is very limited decision making power afforded to parents and the student.

Once the decision is made by the Education Department, the parents have abide by the ruling of the department. This system requires change to enable students, families and teachers to be in a position to work collaboratively and successfully for the ultimate benefit of the students.

Rearing their child with disability is not an easy task for the parents and they have been given the responsibility of giving their best to their child. Life should not be a major battle to fight. Education is the only path that will help mould their future and the schools are the major establishment that plays a significant role in development of each student. Depending on the method of teaching and the successful systems in the student will succeed in learning given the opportunity.

We understand that it is the aim of the education department to produce results; and the intent is of course that these individuals can stand on their own feet to an extent where they are free spirits with dignity and self-respect and have jobs that will provide that prestige.

Teachers are the vehicles of the department that can assist in achieving this. These teachers looking after the disabled students bear a huge responsibility and they need to be accountable, transparent and independently audited and given ongoing professional development training with collaborative approach with parents to make every support student a success.

We hope you are able to read our plea to challenge the status quo and make lives better for all our citizens that are marginally challenged.