

\_\_\_\_\_ 2008

To whom it may concern

DEPARTMENT OF EDUCATION, NSW

We have enrolled our five year old son, Macdonald (Mac) Burns in \_\_\_\_\_ Public School for Kindergarten in 2009.

Mac has multiple, profound disabilities as a result of an acquired brain injury.

Mac has a long family history at \_\_\_\_\_ Public with his Grandfather Wilson, Great Grandmother Wilson (nee Binks) and even Great Great Grandfather Binks (1870s) all attending this school. In fact, the grounds of \_\_\_\_\_ School are on the former farming land of these family members. It is very exciting for us as a family to see him able to attend this school and we write to you in support of integration funding to support his inclusion in this environment.

We offer our full assistance in any decision making regarding Mac's needs. We have intimate and extensive knowledge to share and are committed to him living a valued and inclusive life.

We provide the following information to help you in the process of deciding the level of support that Mac and \_\_\_\_\_ Public School will require.

### **Our Vision**

We have realistic expectations of and for Mac. Because he is so physically compromised, along with significant vision impairment he will require support for the rest of his life to ensure his needs are met. In the school environment Mac will need a modified curriculum with technology being key to his learning, inclusion and potential independence. He will also need 100% assistance in the area of feeding and toileting.

Part of our vision for Mac is that he is an engaged and valued member of the community with choice and respect paramount in his life.

Mac is an extremely good natured little boy. He loves noise, music, boisterous play and chocolate coated ice-cream. He does not like being 'woken up' when he is not ready and has a 'world class' scowl to prove it.

### **Motor Skills**

We work very hard on Mac's physical condition and have seen wonderful changes to date but, as Mac is in the severest physical impairment category, he still has a lot of improvement ahead of him and therefore will require significant assistance to undertake most tasks.

Mac has no independent mobility – he has Cerebral Palsy (severe spastic quadriplegia). Mac is unable to sit independently, has no ability to weight bear and limited (but improving) head control. Mac physical state is one of hypertonia (tight/rigid muscles particularly legs and arms) so, for example, he is unable to 'shoo a fly' from his face or put his hand to his mouth.

Mac is unable to grasp and hold objects but has been using Switch Technology in order to access toys, computers etc.

## Positioning and Mobility Aids

The extent of Mac's physical condition can be understood as follows:

*Mac does not have enough trunk control to sit up independently while simultaneously using his arms/ hands and hold his head up to listen and participate in class activities.*

A range of customised seating will be required, related to the task, to maximise Mac's opportunity for participation, for example:

**MOBILITY:** wheelchair with customised seating  
**FLOOR WORK:** high/low base seating system and/or other seats as appropriate  
**AT DESK:** height adjustable seat with appropriate tilt options

All Mac's seating and other equipment needs will be prescribed by a professional Occupational Therapist from The Spastic Centre, ————— in partnership with us and our intimate knowledge of Mac's changing needs. Mac is currently on the PADP waiting list for his Wheelchair which will address most of these identified needs.

## Sight and Hearing

### HEARING

Mac's hearing is mostly fine. In tests it was considered any hearing loss was in the low tones and well below that of normal communication therefore of no real concern.

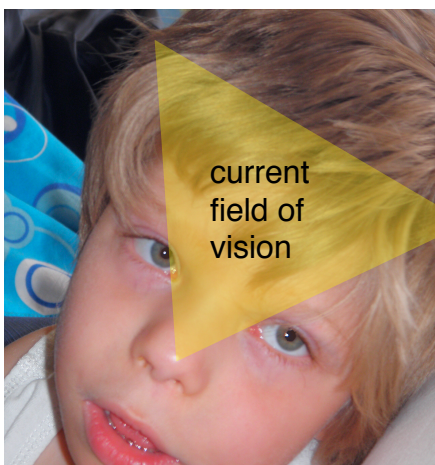
Mac will startle from some sounds which can result in a involuntary muscle spasm (startle causes a head turn to the left then spasm causing head turning to the right) although these are reducing in regularity and intensity.

It is not the loudest sounds that cause the reaction but there is a definite "over-sensitive" response to certain noises. He will occasionally get frightened by the 'bear growl' type noises and will make this very obvious by his facial expression. That being said, Mac loves noise and will always prefer being in a vibrant, noisy room than a quiet environment.

### VISION

The official reports from the Opthamologist is Mac has significant Cortical Vision Blindness can see nothing other than light and dark (letter attached).

However, we believe he has 'intermittent moments of visual clarity' but acknowledge they are fleeting. From our observations we believe Mac has a field of vision in an arc above his nose as indicated left.



Mac likes watching TV and his preferred position is laying backwards and watching it upside down - you can see him fix and follow on the TV when he is in the right position.

We have ordered a wheelchair that has both anterior and posterior tilt options to allow the most flexibility when positioning Mac for activities to take advantage of this 'field of vision'. We use a 32" screen for his computer at home which seems to work well.

As the children, teachers and aides get to know Mac they will learn to identify when he is actually truly focussed with his eyes and then when he reverts to a 'scanning' mode.

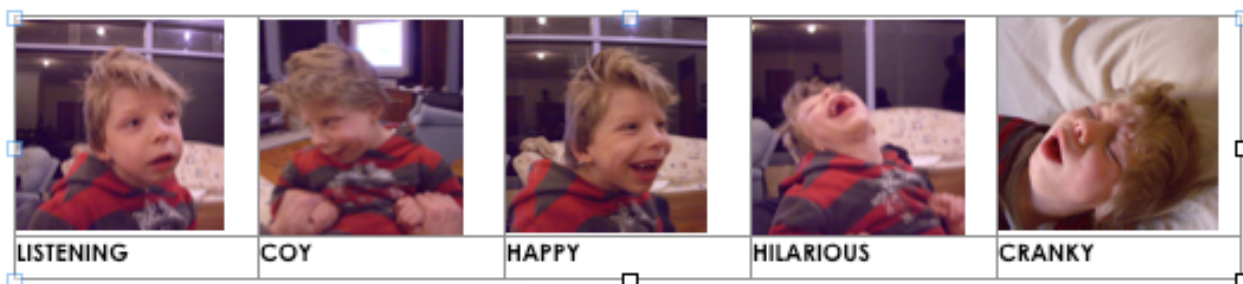
We constantly encourage Mac with the "show me eyes" &

"where's eyes" requests to improve his level of eye contact with those engaging with him. It is also a tool in ascertaining answers from him eg if you ask a question and he makes eye contact with you we accept that as a "yes" and if he refuses to make eye contact we take that as a "no" provided we have 'asked him' for input with his eyes.

Mac will benefit from additional, tactile and/or sensory inputs in his vision based class activities.

### Communication Skills

Mac seems to be aware of much of what is going on in his environment but as he has no significant verbal language or mobility it is very difficult to gauge to what extent. To understand what Mac is trying to express you only have to look at his face. He has a very expressive little face and the intended message, if you take the time to learn how to interpret, is very easy to read.



In fact, some of Mac's peers from pre-school and day care who will transition to school with him will likely be very good 'assistants' to both aide and teacher in helping them learn what he is 'trying to say'.

Mac will also kick his legs to express his feelings and in time you will be able to distinguish between a "cranky kick" and an "excited kick".

Mac also uses his mouth and tongue as a form of communication. He will confirm (or advise) he is hungry by a mouth smacking motion and, depending on the 'intensity' of the mouth smack will indicate how hungry he is. He has recently started poking his tongue out when he 'likes' something eg Ice Cream.

Mac will often "poke his tongue out" when requested to do so.

### VERBAL COMMUNICATION

Mac has appropriate laugh, giggle and squeal sounds when excited particularly when tickled or bounced. He often "sings" along with songs he likes.

Mac's range of sounds is improving but currently limited to "tracheal sounds". We are keen to encourage the use of these sounds for purposeful communication as we believe, if he can master them, they are sounds everyone in any setting will understand.

Some examples are:

SOUND	MEANING	ACHIEVED or DESIRED
go	GO	Achieved when he wants toys to 'go'. Needs greater consistency.
yar	YES	Trying to encourage this use, trying to use the word Yar ourselves and singing a 'made up' song about Yar meaning Yes to him.

SOUND	MEANING	ACHIEVED or DESIRED
ah-oh	HELLO	This is a new sound for Mac and we are encouraging it as a version of 'hello'.
car	CAR	He will regularly repeat this when hearing it on TV/radio or versions of it (Carl for example). We use it as appropriate and encourage him to use it.

We will compile and provide a list of all other 'communication' sounds to Mac's teachers in order for them to understand some of the other meanings behind his verbal communication.

#### **AUDITORY INPUT and SUBSEQUENT INFORMATION PROCESSING**

Mac relies very heavily on auditory input into every part of his day. He has learnt to distinguish "who owns what footsteps" and anticipate their arrival. He knows sound of the 'sliding back door' probably means someone coming to visit him and will give a "happy sounding call" to ensure he isn't overlooked. As we pull up to Day Care or Pre-school he grins broadly in anticipation of attendance yet discerns between these settings and the 'early intervention' setting which he seems to only 'tolerate' and does not give the same response on arrival.

Mac loves music and silly sounds. He will sit with his father playing their songs vocalising throughout. He is able to place emphasis on his sounds making little sounds when the music is soft and/or slow and big sounds when the song is fast and loud. He also is discerning in his 'taste' and will only engage in particular songs. Mac also responds incredibly well to the sounds of other children. He loves listening to podcasts of stories read by other children seeming to enjoy them more than having any adult read to him.

#### **COMMUNICATION AIDS and ENABLING TECHNOLOGY**

Identification of Mac's communication and technology aid requirements will be established in joint consultation with a professional speech therapist from The Spastic Centre in partnership with us \_\_\_\_\_ School and other officials/specialists as required.

#### **Socialisation and Play**

Mac is a very social little boy. He loves other children and loves their engagement and friendship with him. Many of the children he attends pre-school with know how to 'rumble' with him by 'jiggling' his arms, 'scruffing' his chest, patting his face if he is sad (delivering his 'dummy' if he is very upset). The children have been encouraged to make physical contact when they are talking directly to him, and letting him know who they are eg "Hi Mac, it's Ben, do you want to play with my toy truck. It is a tip truck and is yellow and blue".

Mac gets bored (like any 5yo boy does) with play that is too 'gentle' or if he is treated too 'preciously'. It is important Mac is not seen as "sick or frail" (he's not) and enabled to get the most out of any social or play experience. There may be opportunities to incorporate some 'accessible equipment' in the classroom and playground to enable him greater options in this regard.

#### **Personal Care**

Mac will need assistance with all aspects of personal hygiene and feeding. He has modified feeding requirements with a gastrostomy tube for the provision of liquids and top-up feeding and an ability to eat pureed food orally. An appropriate feeding plan will be prepared in line with current procedures at pre-school and long day care and revised/updated as required on an ongoing basis as his needs change.

Mac is incontinent and will therefore require nappies to be changed throughout the day in an appropriate setting.

### **General Comments**

We wholeheartedly support the concept of “investing in all children” (philosophically and financially) as opposed to “warehousing people with disabilities”. No one can guess what Mac’s potential is and we are certainly not prepared to place limitations on him.

Mac has been attending mainstream pre-school and day care centres since he was two years of age. These centres will both be important in his transition to kindergarten.

We will provide assistance, support, insight and ideas to help as best we can. Between us we have some very useful skills that we are happy for \_\_\_\_\_ Public School to ‘tap into’ and help play a part in establishing some great programs to can be utilised by more children than Mac alone.

With the DET’s commitment to Mac’s school career I believe we will see great things from Mac and \_\_\_\_\_ Public School over the next seven years.

Yours faithfully

Shawn Burns & Gina Wilson-Burns

cc: The Spastic Centre  
\_\_\_\_\_ Public School

To the Tune of ‘Skip to my Lou’

## **TALKING MACCO’S TALK**

**Yar Yar means Yes Yes Yes,  
Yar Yar means Yes Yes Yes,  
Yar means Yes Yes  
When talking Macco’s talk**

**Ay-oh means Hello,  
Ay-oh means Hello,  
Ay-oh means Hello,  
When talking Macco’s talk**

**Car means CAR - of course,  
Go means GO - of course,  
GLAAAR means - WHAT GREAT FUN  
Talking Macco’s Talk**

