

WSAI News



Volume 22, Issue 2, Autumn 2017

WSAI Junior Camp

Ruth Brabazon

In early August the first WSAI Junior Music and Activity Camp took place in Mary Immaculate teacher training college, Limerick. It was organised by Fionnuala Tynan and Deirdre Graham, and aided by Kelsey and two students from Mary I.

The children ranged from very young (about 4) up to 15. It was a terrific chance for families to get together. While the children worked away with Fionnuala in the large, well-equipped and bright classroom area, the parents could go next door for a coffee and a chat with Deirdre and family. It was great to sit around the table and talk at length, which we don't often get the chance to do at busier events with the kids in tow!

Some kids came for one day, some for all four days. For Nick it was a great experience. He was one of the older ones and was a

bit dubious and anxious about going, but after a day or so he settled right in and achieved amazing stuff. His concentration improved and he had to be torn away from some tasks, he was enjoying them so much. He enjoyed his swirly drawing too, which is a first!

Fionnuala had arranged a mixture of activities; drawing (swirling crayons to make colourful patterns to music); ball games (to practice gross motor skills); fine motor activities tailored to the child's ability (e.g. putting tops on bottles); and there was a lovely dark tent with fairy lights to retreat to if it all got a bit too exciting!

There was a nice chat around the table over lunch. Of course there was plenty of music too, with each day ending with songs and musical performance.



Nick Brabazon at Junior Camp

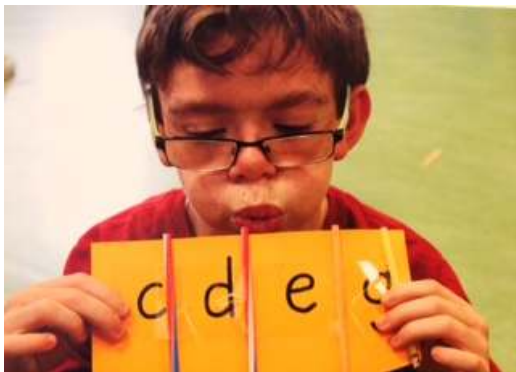
Nicks favourite activity was the TacPac time, which is a chance to relax lying on a mat ,with gentle music playing , while a helper (or parent) fans you with a paper plate, brushes you with a soft mop or steel wool pad. He loved the sensory aspect of that and it helped them all to relax and recover at the end of each day.

Afterwards Fionnuala sent us a detailed report into each child's experience, with lots of tips and things to work on at home. So much work went into this and on behalf of all the parents involved, a huge Thank You to her and her helpers for all their efforts!

Ruth Brabazon

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Nick Brabazon Working at Camp

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Friendship

Deirdre Fitzgerald

I dropped Ed into school this morning. As usual he was happy to go in, and excited to see one of his friends that he had spotted from the car. We entered the hall and immediately Ed made a bee line to two boys who I knew are in his class. The boys were huddled together and chatting. Ed greeted them in his unique and friendly, if somewhat overbearing, way. He walked to them and put his arms around their shoulders. In unison, they looked at each other in an embarrassed way, and they walked away from Ed. My special boy was literally left standing alone in the middle of the hall. Ed stood in the crowded hall, surrounded by children, playing, chatting, dancing – but he was alone. This despite trying so hard to interact with the boys as we have been encouraging him to do.

By their very nature 6-year-old boys are not inclined to accept others who they perceive as different or “strange”. My boy, who loves friends, and who dearly wants to be accepted is not. He is on the peripheral of the boy’s culture. The girls accept him, interact with, and include him. But he craves a little friend. This will be the story of his life. The blood left my head this morning and sadness reared its head again. The crushing reality of his situation was reinforced through that

seemingly innocent act. I could only watch, I could not interfere. What could I have said? Hey you two, play with him? You can’t force children to play as that would make the situation worse by breeding resentment.

What is the solution? I phoned Johnny. He wisely spoke about how we as his parents need to give Ed the tools to deal with these situations in his life. It is inevitable that people will avoid him, and will be unable to understand or interact with him. These are their misunderstandings. We need to teach him to go to the people that accept and celebrate him. We need to teach all our children this. He needs to realise that ultimately when people treat him badly then it is about that person’s own inadequacies and not his. But for now, I am sad, as I will be forever. My precious boy, so full of love, so willing to share it, must find his way in the world himself. I cannot manage his life and his friendships as much as I can’t manage my other children’s lives. That fact fills me with sadness and worry. As his parent’s, we need to fill him with confidence and acceptance of other people’s reactions. It is not easy, but I suppose nothing that is worth something is easy.



Ed and his “best friend”, his brother JJ.

Kelsey’s on the Bus

Kelsey Brannigan

Hi WS friends my name is Kelsey and I am 17 years of age. I am in my final year of Scoil Chiaran special needs school.

This September I started to use the public bus to and from school on my own.



Kelsey Practicing with Dad

I have been practising since last November with my mam and nan.

During the summer we made the decision that it was now or never, I was hoping it was NEVER!

I get anxious thinking about it, I worry about missing my stop, I don’t like standing up on the bus before it stops and sometimes the driver is in a rush. I worry about being seated before the bus takes off in case I fall. The first day I missed getting off at the right stop, but I just got off at the next.

I bring my phone just in case I need to ring my mam or dad. I ring them when I am leaving the school and again when I get home. When I get off the bus I have a 15 minute walk to my house, I bring my purse too and treat myself to a drink in Supervalu on the way up to my house.

I have made lots of friends on the bus and in Supervalu that I can ask for assistance if I am unsure or anxious. All my family and friends are all proud of me using the public bus. Onwards and upwards.

Into Town next, watch this space #kelseybfrequenttraveller#thankgod i’ve a bus pass!



Kelsey at the Bus Stop

Weekend Away 2017

Carmel Daly



Cavan Crystal Hotel

We has a great annual weekend family get together in The Cavan Crystal Hotel this year.

It was held on the weekend of 7th April and 19 families attended. i.e. 65 people a great turnout. It was especially nice to see some new families attending this year. The weekend is a great opportunity for individuals and families of WS people to get together, to socialise and swap experiences and I would recommend it to anyone who is new to WSAI.

During the weekend we had a trip to the cinema and thoroughly enjoyed Beauty and the Beast.

We also went bowling. As usual great fun was had, if anyone didn't play well it was only because they were too busy chatting and having a laugh so we were all winners. That's my excuse anyway and I'm sticking to it!

By all accounts everyone enjoyed a fun filled but relaxing weekend. The highlight as always is the opportunity to meet others in the same situation as ourselves and to discuss challenges and achievements in an empathetic way.

The weekend out is one of our main events and is a great opportunity to meet up with friends old and new in a relaxed and enjoyable atmosphere. I would highly recommend it to all families irrespective of age of persons with WS.

Carmel
086 2074608

Articles for Newsletters 2018

WSAI Committee

I hope that you agree that the stories provided by our WS people are inspirational and that they highlight the wonderful things WS people experience and achieve right across the country.

We would very much welcome contributions from more WS people and member families and are sure that there are lots more fantastic stories out there about how people are coping with WS on a daily basis.

All we need is an email or letter with some photos if possible and we will do the editing and presentation from there. If you would like to contribute then just get in touch with any

member of the committee or just send your material to our email or postal address.

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First WSAI Junior Camp Carmel Daly

The junior music camp was a great success. We had 9 children over four days. We are very grateful to Mary Immaculate College for the use of four rooms free of charge for the week. Deidre met with parents in a parents room, parents could pop in here for tea/coffee and a chat at any stage of the day. This was a very important aspect of the camp for parents to support one another and share experiences.

Fionnuala, with the help of Caroline and Michael, two fabulous final year students in Mary I, worked with the children from 10.00 to 15.00 each day doing a wide range of activities including art, fine-motor skills, gross-motor skills, circle time, music and music therapy. Parents filled in a form initially and based on the priorities for their child an individual education plan was drawn up. At the end of the camp a report was given to parents on the child's participation in the camp. It was a hugely positive experience and the children were fantastic, they made great strides over just four days.

This was our first Junior and a lot has been learned a lot from it. We had a bigger turnout than expected and the general consensus was that it was a very beneficial few days for both parents and children. The need for the provision of workshops for siblings was evident and it is something the team will look into..



Mary Immaculate College Limerick

Fionnuala and her team formulated and provided exceptional IEPs for each child based on how they performed over the 4 days. These have been invaluable in providing a solid foundation for IEPs in school for the children.

Huge Thanks to Fionnuala and Deirdre for all their work on this.

FEWS Camp Italy 2017

Pauline Leahy

The excitement is building up as we head to the airport to catch our flight to Rome DaVinci Airport . There's a lot of chatter of where we are going to stay, how will the place will look and what kind of entertainment we will have, What kind of activities will we have and what else waits ahead of us.

We were greeted by a member of the FEWS team after we landed in Rome. While heading to the bus we met a few more campers only to be told that we are waiting for everyone else to arrive before we head to camp. A lot of tired and unhappy faces unfortunately!

We arrived in camp around 3.30pm as the buses pulled in and when we saw the place, we just wanted to go back home. There were a lot of disappointed faces when we realised this was our home for the week. We got settled in to our accommodation went for dinner and enjoyed the rest of the night . Tomorrow we start enjoying our Camp.

Tuesday morning we head for breakfast and then on to the Adventure Park which was on the camp site . It was not far to travel. Everyone one tried their best at participating with the Climbing Frames, but the height was not to everyone's liking. After lunch some of us went for a stroll along the beach and had a swim in the sea, the water was nice and calm, all enjoyed the day.

Wednesday and Thursday were very busy days with the Camp's Olympic Games and trips out to Dinner at Montalto and lunch at Etruscopolis. Everyone took part in the games tug of war, egg & spoon races, sack race and team goal scoring. We had homemade Pizza at Montalto after our trip around the grounds where we saw the wild Boar and Deer. It was



FEWS Team Italy 2017

such a fabulous sight to see them coming up close to the carriage so we could feed them and take their photos. At Etruscopolis we went to see the museum which was deep underground we saw the paintings and the pottery that they made and how they worked and the houses they built and lived in, after lunch we tried our hand at pottery painting using the same materials that they used in their time.

Friday, Saturday & Sunday we had a Photo Contest, Carriage Drive, Visit to Giardino Dei Tarocchi and Dinner & Disco at the Beach. The Photo Contest took place around the camp where each country had to take photos with a different theme and put their best photo into the competition. Our team won best photo.

Everyone went either on the Carriage Drive or went Horse Riding around the track. Some were lucky enough to go on both and really enjoyed the day.

Disco straight after. Everyone was up dancing and mixing very well, A happy and sad ending to a great week. Nobody wanted to go home and tears of sadness were shed when goodbyes were said.

WSAI Annual Picnic Carmel Daly

This years Picnic in the Park was held in Newbridge House and Farm, Donabate, North Dublin on the 2nd July and by all means it was a huge success.

14 families arrived, almost 60 people, and all were in great spirits thanks in a small way to the beautiful weather. The sunshine that has evaded us for the last few years decided to grace us that day. Patience and perseverance will win out.

There was lots to do and see there. The animals were very entertaining and the farm machinery and hatchery was most interesting. After our walk around the farm we all sat in the picnic area and enjoyed the food provided by Wayne in his chip van. It was lovely to sit around in the sun and chat about anything and everything. Particularly nice to meet new families, all of whom we have met up with since.



FEWS 2017 WSAI Team Alex, Ann Marie, Oskar and Ashleigh

The outing to the Giardino Dei Tarocchi was the best trip of the week. Our time walking around this park looking at the different sculptures and the house were just fabulous. We were able to walk into the house and see how everything was put together it was just unbelievable.

The piece de resistance of the week was Dinner at the Beach and the

WSAI AGM 2017

Carmel Daly

The 30th Annual General Meeting of the Williams Syndrome Association of Ireland will be held in the Crowne Plaza Hotel, Blanchardstown Town Centre, Dublin 15, at 1.30 pm on 11th November 2017.

The AGM will be followed by guest speakers who will discuss topics of particular interest to families/carers of people with WS. While the presentations are in process, we will be holding a music workshop for our Williams Syndrome people and their siblings. This will be followed by tea/coffee and the day should finish up at about 5pm. The hotel has given us a special rate of €139 for a double/twin room inc breakfast (€129 for a single room) on the night of the AGM if anyone would like to stay. Please contact the hotel directly to make a booking.

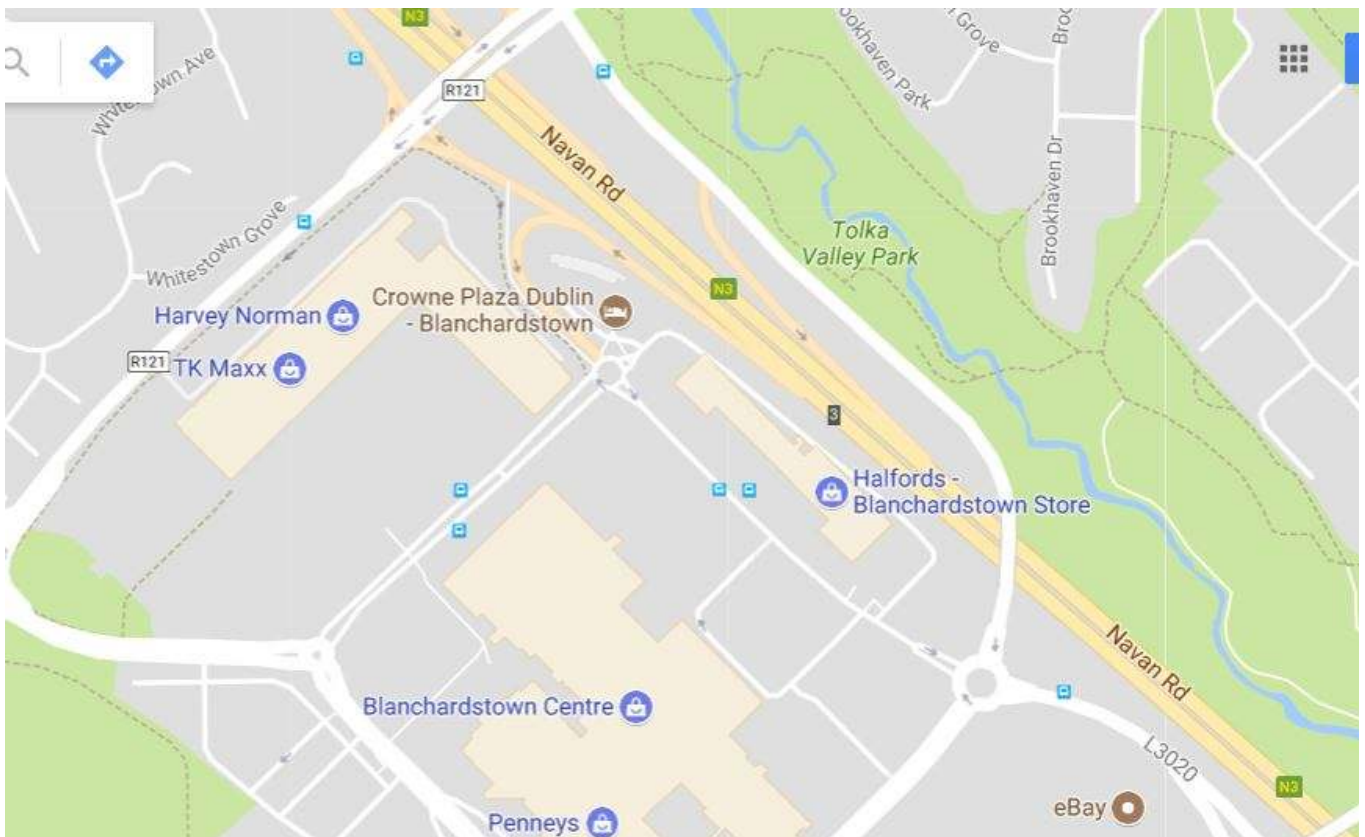
We will have some items for sale on the day, including a lovely collection of luxury hand

made greeting cards and candles, thanks to Fionnuala. And as usual we will have WSAI t-shirts and hoodies ranging in price from €10 to €35 and copies of "Angels at our Table" priced at €10.

As usual we will be electing the Committee and would welcome new members. If you feel that you might be interested please contact me or one of the other Committee members. Even if you don't want to commit yourself at this stage, you may just want to discuss it. If you don't want to become a full Committee member you could come along as an associate member. The level of involvement is completely up to you depending on your circumstance you may just wish to attend meetings for the first year (we hold about 4/5 during the year); there will be no pressure on you to take on any work that you feel you cannot provide the time for but please consider this. The only thing that we would ask is that you commit to attending at least 3 meetings in the year.

I would also like to remind everyone that your annual subscription of €25 becomes due on the date of the AGM and can be paid at the AGM or by post.

We look forward to seeing you and your family on 11th November



Directions for the Crown Plaza in Blancharstown