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Trinity College Dublin

Ollscoil Átha Cliath | The University of Dublin

Conversation Cafés: Advancing Mental Health and Wellbeing for Children with Down Syndrome

Paccar Theatre, Trinity College Dublin

13th October 2022

Executive Summary of the Event

In this interactive Conversation Café, we wanted to hear the voices of the Down Syndrome community in relation to research in the field of Down Syndrome. The event was designed to bring academics, clinicians and advocates together in the spirit of Public and Patient Involvement (PPI). The event comprised of several interesting snapshots about research and developments in a variety of areas that are relevant to the community, along with a parent's perspective on the value and impact of research. Interactive discussion sessions took place between presentations where the audience were asked for their opinions and thoughts about Down Syndrome research, with the objective that participants will help shape future research questions.



Introduction and Background

On Thursday the 13th of October 2022 Trinity College Dublin (TCD), School of Medicine hosted a conversation café focusing on advancing mental health and wellbeing for children with Down Syndrome. The event took place in the Paccar Theatre at TCD and was hosted by Michael Foley, the programme manager for TCD's PPI Ignite office and Beth Corcoran, a parent of a child with Down Syndrome. The aim of the conversation café is to improve the scope of research for children with Down Syndrome by involving the parents advocating for their children and professionals who work with people with Down Syndrome. It is not just about doing research anymore; it's about working with people to develop research that is going to have an impact on

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lives by bringing the experience and expertise of PPIs to research. PPIs have encountered personal situations where they have looked to research to provide answers or advice. Research may have helped them make more informed decisions, it may have made things easier. We want to make sure that when people look to research for evidence or advice that answers are available to them, and that the research that is happening is meaningful and will make a difference.

We had a brilliant turn out with 91 attendees. Our audience comprised a range of contributors including 70 parents/advocates of a child with Down Syndrome (76.92%), 14 professionals who work with children with Down Syndrome (15.38%), 4 with an interest in health policy or health research (4.4%), and 3 with another affiliation (3.30%). The conversation café hosted four academics who discussed their research in relation to the field of Down Syndrome. In between speakers, an interactive discussion session took place where the audience discussed their thoughts on Down Syndrome research.

Program and Speakers

Speaker One: Physical Activity and Exercise Prescription for Children and Adults with Down Syndrome by Professor John Gormley

John Gormley is a professor in the Discipline of Physiotherapy at TCD. His research focuses on the impact of physical activity on the management and treatment of disease. Individuals with Down Syndrome endure specific challenges that may compromise their ability to exercise such as issues with their cardiovascular, respiratory, musculoskeletal and endocrine systems as well their cognition and mental health. Issues such as underlying muscle weakness may inhibit an individual with Down Syndrome to carry out exercise. Aerobic Exercise has been shown to improve performance in specific tasks and Aerobic exercise programmes have also been shown to have beneficial effects on balance. It would appear that a combination of Aerobic exercise and Resistance exercise is best to achieve significant changes in Fitness. Other studies have suggested that cognitive functioning may improve with exercise, but these findings are

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mixed in those with Down Syndrome. Overall, high-quality studies are required to investigate the impact of exercise on the health and wellbeing of adults and children with Down Syndrome. As with all exercise programmes long-term adherence of exercise needs to be addressed. The current health guidelines do not address the complexity of Down Syndrome and an exercise prescription must be individualised to meet each person's needs. The aim of future research is to remove the fear of exercise and to promote engagement through influencing health policy and improving inclusivity from sporting bodies.

Speaker Two: Inflammatory Biomarkers in Children with Down Syndrome by Professor Eleanor Molloy

Eleanor Molloy is a professor of Paediatrics and Child Health at the School of Medicine, TCD. She leads the Infant Down Syndrome clinic in Children's Health Ireland (CHI) Tallaght Hospital and is a principal investigator for a research group investigating Down syndrome, Inflammation and clinical Outcomes (DISCO). The DISCO group combines expertise from a variety of disciplines and organisations including paediatrics, neurodevelopment and PPI. The outcomes of children with Down Syndrome are mixed, therefore the DISCO group aim to develop guidelines that will help inform the clinical prognosis of children with the condition. In particular Prof Molloy's research group investigates the impact of inflammation on the immune system – why children with Down Syndrome are more prone to infection? Multiorgan dysfunction – is every organ affected in the same way? Do children with Down Syndrome benefit more from vaccines? How do we talk to parents about these clinical issues? Prof Molloy emphasises the need to involve more families and children in research and promote working together to write academic papers on issues relating to Down Syndrome for families and healthcare workers.

Panel Q&A – Round Table Session One

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After the first two speakers, we invited the audience to ask questions and share their thoughts on the research presented to them –

A parent of a 15-year old girl with Down Syndrome expressed concern about her daughter's weight gain despite being very active in extracurricular sports. She asked if children with DS are predisposed to put on weight and asked for advice on limiting food intake.

Professor Gormley stated that exercise on its own is not effective in keeping down weight, it takes a lot of exercise to expend calories. Professor Molloy proposed that weight gain may be related to a dysregulation in the immune system and may impact the way people with Down Syndrome metabolise food.

Another parent of a child with Down Syndrome asked if there are any good therapies for celiac disease as the condition is complex and may have an impact on intellectual disability in those with Down Syndrome?

Professor Molloy suggested that it can be controlled by a change in diet. There is a genetic screening that can be taken at birth, they discuss whether it is worth taking this test. Some may be reluctant to use biologics for a disease that can be controlled by diet.

A parent of a child with Down Syndrome asked about the research concerning aerobic exercise and resistance training: How do you measure fitness? Can you recommend tasks for children?

Ann O'Sullivan, a Physiotherapist from the Down Syndrome Centre in North Dublin recommended floor exercises, exercises that use the child's own body weight and basic activities such as jumping. YouTube has a lot of activities for children. As they get older, they start to understand how to do active exercises.

Speaker Three: Down Syndrome Associated Arthritis (DA) by Dr Mary Canavan

Mary Canavan is an Assistant Professor in Immunology at the School of Medicine, TCD. She works in the Department of Molecular Rheumatology led by Professor Ursula Fearon where

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they investigate the key mechanisms involved in Down Syndrome associated Arthritis (DA). The prevalence of DA was not very well known, with the first case being reported in 1984. Recent research suggests that there are higher incidence rates of arthritis in those with Down Syndrome. The identification of DA is typically delayed meaning that significant damage may have already occurred at the time of diagnosis. Scientific research has been conducted to investigate the immune cells in the blood of those with Down Syndrome. The number of pro-inflammatory and anti-inflammatory immune cells in the blood is analysed to see if there are significant differences compared to those with Juvenile Rheumatoid Arthritis. Overall, an imbalance in inflammatory immune cells has been observed and those with DA have more proinflammatory cells. Current treatments include medications used for adults with arthritis, but alternatives are needed as not all children with DA respond to these medications. Future research in this field aims to recognise other proteins that may contribute to DA and to improve our understanding of what drives the disease in order to develop more effective therapies.

Speaker Four: Language Development in Down Syndrome by Dr Jean Quigley

Jean Quigley is an Assistant Professor in Developmental Psychology and co-director of the Infant and Child Research Lab at the School of Psychology, TCD. Her research interests are in language development, with particular reference to early first language acquisition and to developmental disorders including Down Syndrome. The language profile of children with Down Syndrome is relatively well defined. Children with Down Syndrome tend to exhibit better comprehension compared to expressive language skills. Their vocabulary is typically better than their grammatical skills. Motor difficulties may impact articulation, phonology and intelligibility, whereas weaknesses in short-term memory may influence the development of grammar skills. The observation of parent-child interactions has helped us better define the infrastructure for language acquisition and development of children with Down Syndrome. Parents can use the words the child knows in a variety of frames and sentence types to help develop grammar and engage in conversational turn-taking with emphasis on child-initiated

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turns. Imitate, expand, repeat and recast your child's words. Provide opportunities for symbolic play and do not simplify your language any more than you would for a child of a similar age.

Panel Q&A Round Table Session Two –

After the two presenters, the audience were invited to ask Dr Mary Canavan and Dr Jean Quigley questions about their presentations:

A parent of a child with Down Syndrome stated that her son will very often interrupt conversation. She struggles to get her son to engage in turn-taking, are there any other strategies that can be used to develop turn-taking?

There are lots of techniques and strategies that can be effective depending on your child's learning style, for example, using direct language and stating explicitly whose turn it is, modelling turn-taking in games and being very explicit each time a turn is taken, keep turns short so the child doesn't have to wait too long and engaging older siblings & friends of the child in turn games.

A third parent asked Dr Jean Quigley her thoughts on the use of Augmentative and Alternative (AAC) communication devices, do they help with language acquisition?

Dr Quigley suggested that if the child can work the device and they are motivated to use it the devices can be beneficial in facilitating communication, not just in the child but it is also reinforcing for their conversational partners.

Speaker Five: A Parent's Perspective by Beth Corcoran

Beth Corcoran is programme manager for a research group based in the School of Medicine at TCD, she is also mother to Rosa, an 11-year old girl with Down Syndrome. Through her work, Beth has learnt the value of research to society and how research can help inform personal decisions. She now actively contributes as a parent representative for Down Syndrome research. Beth spoke of her experiences raising her daughter and the decisions she has had to face along the way. It is a tradition for Beth's family to attend Gaelscoil, so when Rosa reached

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school age she wanted to make an informed decision about whether she should send her to a Gaelscoil or an English medium school. If Beth had the access and insight to research that she has today, she feels that she could have used research as a tool to better inform her decisions on Rosa's schooling. Beth hopes that research can be accessed by those who need it, and that it can be used as a community tool that shifts the conversation from hard science, to informing real life decisions and that it can also be used to support advocacy for better implementation of services.

Beth and Michael were joined by Mei Lin Yap, a woman with Down Syndrome. A number of impressive accomplishments have been made by Mei Lin. She is a graduate of TCD, she works for HR company CPL and has been an ambassador and public speaker representing those with Down Syndrome since the age of 13. On top of these accomplishments, Mei Lin is a swimmer and has qualified to compete in Down Syndrome swimming competitions at an international level. Mei Lin has shown us that people with Down Syndrome also have aspirations and that those dreams can come true.

Conclusion and Recommendations

We received a number of positive comments from our audience about the conversation café. Based on the survey distributed after the event the attendants found the talks to be informative, engaging and interesting to hear the advancements in relevant areas of Down Syndrome research. The collaborative aspect of the event was a highlight with researchers, clinicians and parents of children with Down Syndrome coming together to express their enthusiasm and partnership in the development of research. Collaboration with other Irish universities such as UCC and NUIG has been suggested. The parents appreciated the opportunity to network with scientists, health professionals and other parents of children with Down Syndrome. They appreciated the willingness to take on board the experience of parents to influence future research. The audience enjoyed hearing the voice of a mother of a child with Down Syndrome, and Mei Lin of course, was the star of the show. Many saw her talk as a

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highlight, she is a wonderful public speaker and an inspiration to parents and professionals working with people with Down Syndrome. Overall, most participants wanted more time to ask questions and network with others. It has been suggested that the event could take place annually over a whole day or half day at a time better suited to parents.

Suggestions for future Down Syndrome research:

- Investigating educational settings such as mainstream schools vs special school
- Best education methods for reading writing, numeracy
- Learning new skills (activities such as swimming, learning new instruments)
- More defined research in areas of cognition (such as memory, attention, executive functions)
- Speech and language therapy, current research and advancements
- Dyslexia
- Behavioural Issues
- Sensory Processing
- Dealing with mental health
- Social skills development
- Menstrual hygiene for girls with poor fine motor skills
- Puberty
- Sexuality
- The investigation of sleep disturbance (that is unrelated to obstructive sleep apnoea)
- Diet and nutrition
- Managing weight
- Down Syndrome as an autoimmune condition
- Inflammatory bowel disease
- Food intolerance
- Microbiome
- Atlanto-axial instability

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- Contenance
- Hearing
- Aging with Down Syndrome, increasing life expectancy
- Prenatal and postnatal diagnosis and delivery of information by health care providers

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