Moving Forward Together

annual report

2015/2016
INTRODUCTION

As Autism diagnosis rates are rapidly increasing in Northern Ireland, our services are more vital than ever. Autism NI helps people affected by Autism through funding research, driving change through advocacy, setting up vital Support Groups across Northern Ireland, and facilitating professional education and services that help people with Autism and their families move forward. We are continually adapting our services to support the 30,000 individuals affected by Autism in Northern Ireland.

Our Year In Numbers:

- **Autism research engagements with professionals:** 1,700
- **New ‘likes’ on Facebook in 2016:** reaching up to 85,000 people online every month
- **32 policy meetings with government bodies to lobby Autism services across NI:**
- **20 groups throughout NI are trained over 2,000 delegates per year:**
- **3,200 families supported across NI:**
- **27% increase in Membership:**
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CHAIRPERSON’S REPORT

I feel this year is very much a ‘tale of two parts’. The first part of our journey shows the Charity continuing to grow in size, strength, stature and strategy with our services being needed more than ever. In particular our RAFT service has proven to be invaluable to so many families within the Northern Trust area and I’m delighted this service will continue to make a difference to so many more families. Our ultimate aim is to extend our RAFT service throughout Northern Ireland. We also look to continue the development of our Parent Support Network with new groups being set up and developed on an annual basis. Our aim is to provide support for local and isolated Autism communities across Northern Ireland.

However, the other side of the journey has proved to be very challenging. I refer to the inadequate implementation of the Autism Act (NI) 2011, the failure of the Department of Health to engage with the Autism community and the lack of committed strategic leadership across Health and Social Care.

MLA members of the All party Group on Autism (APGA) at the NI Assembly support our deep concern that the Autism Act is not being implemented properly by those responsible. For example, there is a lack of measurable targets, funding, scrutiny and accountability. We will continue to campaign until these issues are resolved satisfactorily and with the best interest of the Autism community. We endeavor to keep you informed of future developments.

On conclusion, it has been a very busy and productive year for Autism NI and I express my gratitude to my fellow Trustees, the staff team, volunteers and all our supporting funders and fund raisers. We look forward to building on last year’s success and implementing our vision of an equal society in Northern Ireland for those living with Autism.
To infinity and beyond: My story

Back in 1992, I was the first professional employed in Northern Ireland with a sole ASD remit. There were no books on Autism in the public library system and knowledge was poor. Since those early days I have been presented with many unbelievable opportunities; from meeting the most inspirational legends in the worldwide Autism movement including Dr Lorna Wing OBE, Dr Judith Gould and Temple Grandin, to addressing audiences in each of the Parliaments and National Assemblies across the UK as well as Capitol Hill in Washington DC and the European Parliament in Brussels.

All of this activity has had one single aim – to improve the interest in and access to knowledge on ASD for professionals and to secure informed support for families. Autism NI was pivotal in developing the first ASD services in Northern Ireland.

If I rewind to 2011 when the Autism NI-led lobby saw the Autism Act (NI) 2011 enacted, it became evident that the next phase would be challenging. The Broken Promises Report catalogues just how challenging the next few years will be and it will need all our resources, all our reserves and all of our resolve if we are to effect the full implementation and release the real potential of the Autism Act.

And so it is that my retirement in 2017 includes my next challenge for Autism NI (PAPA) as a Special Advisor with a focus on the lobby and research.

So the lyrics of the Eagle's song ‘Hotel California’ echo in my mind right now:

“You can check-out at any time you like, but you can never leave.”

CHIEF EXECUTIVE’S REMARKS

“Io infinity and beyond!”

I begin this year’s CEO remarks with a quote from the well-known philosopher and cartoon hero Buzz Lightyear with deliberate purpose.

As Autism NI leaves behind its 25th Anniversary Year, my own 25th anniversary as its CEO approaches as does my retirement date. As these are my final ‘Remarks’ in our Annual Report, I am fully grasping the opportunity to set out our agenda for change.

The last five years have born witness to a surreal culmination of sustained pressure for recognition of ASD and Autism NI; such as earning the greatest collective achievement by Autism NI in its history – the Autism Act (NI), obtaining an Honorary Doctorate for the CEO from Ulster University in recognition of pioneering research in ASD, the Ministerial appointment of the CEO as Chair of the NIASRAC and an MBE for the CEO in recognition for services to Autism.

We aim to continue to rise to the challenges of the future from a firm foundation of good governance and commitment to our Mission and Vision.

To infinity and beyond: Autism NI

- Developing further our expertise in the area of early intervention as well as family support through community development in our network of Support Groups and the revitalisation of our Advice Line Service.
- Continuing our enviable position as the lead research based ASD service innovator in NI in areas such as Criminal Justice and Early Intervention and on issues such as Girls and Autism and access to employment.
- Maintaining our reputation for fair advocacy, grassroots lobbying and persistent campaigning on issues of social injustice across the Northern Ireland Autism community.
- Listening and responding to our members, our supporters, funders and our network of active Support Groups.
- Further developing service partnerships to address the increasing need for ASD services and an accountable service infrastructure.

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CAMPAIGNING

ALL PARTY GROUP ON AUTISM (APGA)

The focus of APGA meetings has changed dramatically over the past year. In September 2015, Autism NI presented a paper on concerns relating to the failure of the NI Executive to implement key elements of the NI Autism Strategy. The core concern was that services were fragmenting rather than developing due to a decrease in funding. A series of meetings with DHSSPS officials including the Permanent Secretary followed, culminating in a meeting with the Health Minister in January 2016. In February, Minister Hamilton MLA announced a £2m investment in ASD services. APGA also provided evidence to the UN Committee on the Rights of People with Disability.

Going forward: The 2016-21 NI Assembly mandate witnesses a refreshed APGA membership with a number of longstanding and loyal MLAs retiring from Stormont or not returned in the May 2016 Election. Special recognition and thanks to Dominic Bradley MLA SDLP (APGA founding Chairperson), Kieran McCarthy MLA Alliance (APGA founding member) and Jonathan Craig MLA DUP (APGA Vice Chairperson) for all their contribution and dedication to the Autism community over the years.

THE NI AUTISM STRATEGY RESEARCH ADVISORY COMMITTEE

Autism NI’s CEO (Dr Arlene Cassidy MBE) is the Chairperson of the NIASRAC, by appointment of the Minister for Health. The NIASRAC meets quarterly to respond to work delegated to it by the cross-departmental group that is responsible for the implementation of the Autism Strategy. The NIASRAC promotes quality research as an essential element for service development decisions.

ASD RESEARCH HUB

The Autism Research Hub (UU) is a partnership project between UU and Autism NI aimed at stimulating multi-disciplinary research collaborations and international partnerships for Autism that promote the culture of evidence based practice for future ASD service development in Northern Ireland.

THE BROKEN PROMISES CAMPAIGN

This campaign partnership between Autism NI and the National Autistic Society NI began in September 2015 following Autism NI’s presentation to the APGA categorising DHSSPS failures in the implementation of the NI Autism Strategy. Shared concerns made working together the best option for our joint mission. Both Charities officially launched the Broken Promises Report to the NI Assembly on 31st May 2016. Initially Autism NI and the National Autistic Society NI delivered joint presentations to Permanent Secretaries of key NI Executive Departments (DCAL, DE, DARD and DOE) and shortly after held a joint Hustings event where parents and professionals expressed their concerns about Autism services in NI. A joint presentation was then delivered at a DHSSPS workshop.

Since the launch of the Broken Promises Report, both Charities have held joint presentations to key NI Assembly Committees underlining substantial need for Autism services in NI and the All Party Group on Autism (APGA) requesting legislative action to address lack of funding and independent scrutiny.

OUR INTERNATIONAL PARTNERSHIPS

Meetings in 2014/15 with colleagues from the Autism Society of America and the national ASD Charities in Scotland, Republic of Ireland and Northern Ireland has resulted in a number of positive outcomes. We have developed a strong partnership between Scottish Autism and Autism NI focusing on exchange of best practice and resources. We also visited Scottish Autism’s Alloa area where we delivered KEYHOLE® Intervention training to their staff. Autism NI also received an extended invitation to join the Autism Alliance UK which is a collaborative network of the major ASD organisations across the UK.

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UK ‘CHAMPION OF CHANGE’ WINNER

In 2015 Autism NI won the national Lloyds Bank Foundation ‘Championing Change’ Award. This award honoured Autism NI’s years spent campaigning to bring in legal recognition of the condition that culminated in the Autism Act (NI) 2011 and worked tirelessly with parents and politicians across Northern Ireland to bring about this legislation.
FAMILY SUPPORT

Our Family Support Service is our longest established service. Autism NI understands that many families face a number of challenging issues and as a parent or carer it can be very isolating at times. Our Family Support Service recognises an ongoing need for provision within local communities. We will continue to provide the skills and energy needed to make sure as many families as possible have access to the right support and services. Over the past year our Family Support Service has delivered 41 free Family Support workshops across Northern Ireland, developed seven new Support Groups in areas such as the Glens, Carrickfergus and Dundonald, and also provided advice and support for over 2,300 families. Our Family Support team also delivered Autism Awareness talks to local community groups and attend information stands at local events to educate the wider community about Autism.

INDIVIDUAL SUPPORT

Due to the increase in diagnosis rates, our Advice Line is a much needed service for families wanting advice on key issues including education, behaviour management, diagnosis, transition stages, statements and housing.

Our Link Workers provide a listening ear, support and signpost callers to appropriate services in their area. They also offer free information and support packs containing directories of local services and leaflets on how to manage key issues such as eating, toileting, behaviour and play. In 2015 the Advice Line received over 2,300 calls, emails or individual visits. This is an increase of 183%, showing the need for this vital service.

GROUP SUPPORT

Our Family Support team co-ordinate and develop effective Support Group networks across Northern Ireland, which continues to be the bedrock of our services. Autism NI’s Support Group network provides a life changing forum for parents and other family members to exchange ideas, share experiences, offer mutual support and discuss different aspects of Autism and its effects on family life. Our Support Groups also receive staff support in complying with legislative regulations, insurance and finance as well as the regular advice on and access to training workshops. Autism NI continues their vital partnership with Positive Futures to provide summer schemes and youth clubs for our Support Groups, and much needed social outlets and respite for families.

Family Support Groups in your area:
Antrim, Ballymena, Bangor, Carrickfergus, Strabane, Derry, Downpatrick, Dundonald, Dungannon, Newtownabbey, East Belfast, Fermangh, Glengormley, Lisburn, Maghera, Newry, Coleraine, South Down and Cushendall.

MEMBERSHIP

We’ve seen a steady increase in new members in 2015/16. Our growing group of members help us improve our support and services for families living with Autism across Northern Ireland.

Our members receive access to the latest news stories, training courses and services we deliver as well as priority queuing and discount into specific attractions across Northern Ireland including Belfast Zoo and W5.
2015-2016

TRAINING

COURSES

During 2015/16 Autism NI’s Training & Consultancy Department delivered a range of courses throughout Northern Ireland to over 2000 participants made up of parents/carers, family members and professionals.

The Fundamentals of Autism course is a popular workshop attracting parents, carers and professionals from organisations such as Unison, Action for Children, and various Councils. We have also seen an increase in demand for individualised in-house training for organisations on a range of Autism-related topics depending on the organisation’s needs.

The two-day Growing Up, Health Awareness and ASD workshop has a course content satisfactory rating of 98%. The workshop was regularly delivered regionally with numerous participants receiving a comprehensive portfolio and relevant resources. In 2015/16 there has been a continued training demand from nurseries and day-care centres, including ‘Structured Play’ training and the two-day early intervention ‘KEYHOLE®’ workshops, with many delegates completing a Level 2 AQA award. Autism NI is also working with the Regional Childcare Partnership to deliver a number of courses regionally for their training prospectus.

Specialist Courses explore a range of particular issues relating to Autism. These courses are run by trainers with professional expertise in areas such as sensory processing, social skills, social stories and comic strip conversations, understanding and promoting positives, behaviour, self-care and communications and ASD.

PARTNERSHIP BUILDING

Autism NI is working with a number of organisations such as Unison, Action for Children, and various Councils to ensure training is delivered to organisations regionally for their training needs.

ACHIEVE AN AQa AWARD IN AUTISM

Autism NI continues to offer and add new accredited Autism specific qualifications through the Assessment Qualification Alliance (AQA). This is the largest awarding body in England and Wales. An AQA accreditation is a recognised agreed standard showing employees commitment to enhancing their organisation’s quality of services. In 2015/16, there were 371 delegates who achieved an AQA Level 1 or Level 2 Award, a 50% increase from the previous year.

YOUNG PEOPLE, AUTISM AND CRIMINAL JUSTICE PROJECT

Autism NI was granted a further year’s funding from the Big Lottery in 2015/16 to deliver this project regionally.

In order to reach and support as many young people, families and professionals as possible, we developed two specific areas of this project across Northern Ireland.

1. We have continued to deliver Autism Awareness training and support resources regionally to PSNI officers and other Criminal Justice Agencies. In 2015/16, a total of 444 individuals attended our Autism Awareness training.

2. Our very successful ‘Skills for Staying Safe’ programme was made available regionally to trainers working with young people. Our trainers developed and delivered a ‘Training for Trainers’ programme to 225 trainers from various voluntary organisations, community and youth groups and schools. This training will empower these agencies to deliver ten tailored sessions on the ‘Skills for Staying Safe’ programme and also gives the young people they work with the opportunity to undertake an AQA accredited award in Level 1 personal safety.

From the legacy of this project, Autism NI will continue to provide useful resources to help young people stay safe in the community, at home or in school.

• Our ‘We Think Safe’ website provides safety activities, facts and education for young people in an accessible and fun way and can also be used by parents or professionals to help them teach young people about safety. To visit this website, please go to www.wethinksafe.com

• The Autism Alert card enables the cardholder to identify themselves as having an Autism Spectrum Disorder. These now come with a new ICE (In Case of Emergency) wristband, which allows parents/carers to write their contact phone number in case of emergencies. In total, we have issued 430 Alerts Cards for young people to carry with them and show when necessary.

• From the project, we have also developed an ‘Autism Top Tips’ mobile responsive website (www.autismtoptips.com), which can present itself as an ‘App’. This gives a quick and general awareness on Autism for parents and professionals.
The RAFT service is a partnership venture, led by Autism NI, which aims to build and strengthen relationships for families of children with Autism aged 12 and under. The RAFT service (which delivers on the KEYHOLE® programme of Early Intervention) supports families in the Carrickfergus and Newtownabbey area in a number of ways:

- Encouraging early childhood intervention through a programme of practical skills training
- Training courses for parents and family members
- Support Groups for family members in the community

Families referred to the RAFT service will engage in a home-based early intervention programme for up to six weeks. These meetings will provide family members with practical tools and support to manage their children’s behaviours, play and socialisation. Early intervention is crucial for all children with ASD as it will improve their social communication and interaction skills. From the start of the service in February 2015, 110 families have benefited from the RAFT home intervention service. With 60 families currently on the waiting list, we aim to support 550 children and their families over the course of five years.

TRAINING AND INFORMATION SESSIONS

The RAFT service provides a range of ‘ASD information sessions’ to parents/carers, extended family members and friends who have an interest in Autism and want to build up their knowledge, skills and coping strategies.

The RAFT project have also provided ASD information sessions and training opportunities to professionals from within the Northern Health and Social Care Trust, our partner organisations and even local schools in order for them to meet the needs of families and young people affected by Autism.

GROUP SUPPORT

Ongoing community support is made available for families involved in the RAFT service with local Support Groups in Carrickfergus and Newtownabbey. During the Support Group meetings parents share knowledge, engage speakers of interest and organise group outings to reduce the social isolation that many Autism families face on a regular basis.

RAFT service user comment:
“I don’t know what I would have done without the RAFT Service. It was there at a time when I felt lost and overwhelmed by the amount of information about ASD. I was still coming to terms with the diagnosis and what it meant in the longer term but ultimately I just wanted to know how I could best support my daughter. An Autism NI worker came out and really focussed her experience and knowledge on what would work best for my child, and our situation.”

I looked forward to her visits, which were always so positive and reassuring. She brought resources that not only worked but she also provided insight as to why they worked, and provided further information that I could follow up on.

The resources also gave me and my eight year old daughter a good basis to discuss and implement support needs outside the family environment, especially in school. This was an invaluable service for my family provided by Autism NI, at the time we needed it most.”
In January of this year insurance company Allianz signed a two-year Charity of the Year partnership with Autism NI. Since then the team have held a ‘Wear It Blue’ day, bring and buy sale, barbeque, participated in the Lisburn Half Marathon and most recently a group of ten took part in our Mourne Madness Trek. It doesn’t stop there as the Allianz team have lots of fun activities and challenges set out for the rest of the partnership.

The year-long partnership which began in April will provide Autism NI with a valuable opportunity to take advantage of CastleCourt’s busy city centre footfall to raise awareness and funds. Autism NI and CastleCourt have already organised some exciting events, which included a special focus throughout World Autism Awareness Day, when CastleCourt lit up the centre in blue. CastleCourt also provided the venue for a successful Static Cycle Challenge and Football Frenzy event, which allowed shoppers to show their support in a fun way.

In June this year the partnership between Autism NI and Sainsbury’s Forestside ended with the store raising a staggering £12,000 over the year-long partnership. This included all sorts of wonderful fundraising ideas from bag packing to a sponsored cycle. The customers and staff of Sainsbury’s Forestside really got behind Autism NI and pulled out all the stops to raise much needed funds and awareness in-store throughout the year.

FUNDRAISING

WEAR IT BLUE
Northern Ireland turned BLUE on 2nd April for World Autism Awareness Day. Autism NI encouraged everyone to don their blue gear for the day and donate. Many local businesses showed their support and held a ‘Wear It Blue’ day in their offices, raising much needed funds and awareness of Autism.

MOURNE MADNESS
A group of 38 trekkers joined us this year to climb Slieve Donard. Some adventurous trekkers took their challenge even further by summiting Slieve Commedagh and Slieve Bearnagh on the same day, reaching an impressive 20km on foot.

SNOW CAKES
During the festive period, the Snow Cakes for Autism campaign was a wonderful success and between local businesses, families and friends it raised much needed funds and awareness. Snow Cakes provided a great platform for fundraisers to enjoy a cup of coffee, a sweet ‘treat’ and an opportunity to make a difference to families within their local area.

CASTLECOURT
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RAINBOW BOUNCE
Many Primary Schools across Northern Ireland continued their support for Autism NI by participating in our Rainbow Bounce initiative. Due to the increasing number of school-aged pupils being diagnosed, the initiative got pupils involved in learning more about Autism by taking part in reading sessions and a child-friendly presentation. Pupils also took part in a ‘sponsored bounce’ and had the chance to win Autism awareness merchandise including our wristband and Rainbow Bear.

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MEET OUR PATRON: ADAM KEEFE
Patron of Autism NI, Adam Keefe is the Captain of the Stena Line Belfast Giants and over the past year has extended his help to the Charity, in raising funds and much needed awareness in Northern Ireland. Back in October Adam took on his ‘Sober for October’ challenge and raised £1820.17. Since then his team have held golf tournaments, yoga sessions and supported Autism NI through an Ulster University business group.
As well as this Adam has loaned his help to a number of fundraising challenges including bag packs and even a static cycle. Not one to shy away from helping out we caught-up with Adam to get a bit more about himself and what drives his success.

RAISING AWARENESS ON THE BIG SCREEN
Autism NI joined forces with the Movie House Cinemas to promote an Autism awareness advertisement which was shown before each movie screening for the entire month of April. Alongside the Movie House Cinemas, a number of local cinemas also increased the number of ‘Autism friendly’ screenings during Autism Awareness Month and will continue to provide these screenings throughout the year.

RAISING AWARENESS

RESOURCES AND MERCHANDISE
Autism NI has a range of Autism awareness merchandise available on our shop website. These resources are often used by Support Groups to generate income for their activities and trips. Our Autism merchandise is a great way to visually support Autism in Northern Ireland and help us raise awareness within the local community. We also hold a range of practical resources at our central office, including Rainbow Resource Kits, a library of Autism-related books, timers and sensory aids.

FIND US ONLINE
Our website (www.autismni.org) is a great source of information on Autism and includes research publications, information on ‘play’, latest news stories, training opportunities, family support workshops and different information leaflets on Autism. The latest news stories and upcoming events can also be followed on our Facebook Page (www.facebook.com/AutismNI), Twitter page (@AutismNIFAPA) and Instagram (autism_ni).

ANNUAL REPORT
2015-2016

Where are you from? I was born in Brampton, Ontario Canada. I lived there until I was about 15. Since then I’ve been bouncing around around Canada and the United States playing Ice hockey until I landed here in Belfast five years ago.

What do you love about Northern Ireland? I love the passion this country has and how loyal they are to their sporting teams. The history that lives and breathes within it is immense as well.

What is your greatest achievement? Being Captain of the Belfast Giants for four seasons now is something I’m pretty proud of as I recognise the importance of this team to the Northern Ireland community.

What drives you to do so much Charity work? It feels good to help and breathes within it is immense as well.

What is your one super power? Flying would be a nice one to take on. It would certainly make the early morning training sessions a lot easier to get to.

What is on your bucket list? Too many to name. I love to travel and love to see the history out there. Maldives, Rome, safari in Africa just to name a few.

Who are your heroes and why? My brother is someone I’ve always looked up to. Someone who’s always set a pretty good example of work ethic and achieving his goals. He will soon be a coach in the NHL.

What is your favourite food? I guess it depends which day you catch me on. If it’s a healthy day, it’s likely to be sweet chilli salmon with sweet potato fries and veg. On a cheat day definitely Pizza!

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Autism NI’s experience of partnerships extends right back to its origins as a ‘parent and professional’ partnership organisation. Our wide range of partnerships across various service organisations ensures that Autism NI has had an impact on areas including; early intervention, training and education, the Criminal Justice System, research, advocacy and employment.

AUTISM ALLIANCE UK

In 2016 Autism NI was very privileged to be invited to be part of the Autism Alliance UK. We feel this will be a strategic alliance to share the latest Autism findings between the four nations of the United Kingdom. As Autism research and findings are constantly being updated and changed, it is imperative to retain a strategic alliance with other Autism organisations that have a similar focus of being at the forefront of commissioning new research and designing new innovative services. This alliance will now give Autism NI the opportunity to showcase their own work but gain external knowledge and best practice from leading Autism organisations.

Autism Alliance UK is the main UK network of specialist Autism organisations committed to improving the lives of people with Autism and increasing their skills and independence.

The aims of Autism Alliance UK are to promote the development and effectiveness of Autism specific services and to provide advice and support to member organisations. Autism Alliance UK also works to raise awareness of Autism to members of the public locally and nationally.
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Tel: 028 9040 1729
(Option 1) - Family Support and Advice Line
(Option 2) – Training and RAFT Service
(Option 3) - Fundraising, Marketing and Events
(Option 4) - Chief Executive & Finance

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