RESEARCH AUTISM
IMPROVING THE QUALITY OF LIFE
IDENTIFICATION  INTERVENTION  INCLUSION
A DECADE OF DISCOVERY
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As an ardent and longstanding campaigner for autism, I accepted without hesitation the invitation ten years ago to become a Founder Patron of Research Autism. At that time, the need for a research organisation which focussed on the day-to-day issues that affect the lives of people with autism was very clear to me.

Over the past decade, as that need has grown, Research Autism has risen to the challenge. The charity has made extraordinary progress in furthering the cause of autism by undertaking high quality research, and providing trusted and impartial information for the benefit of the thousands of families affected by the condition.

At the heart of all that Research Autism does is a firm belief that the needs of individuals and families should drive the research agenda. With a body of research established, and growing numbers accessing their information service, Research Autism has established itself as an authoritative voice in the world of autism. By bringing together people with autism, their families, researchers, clinicians and others in a collaborative endeavour, they are now considered a beacon of excellence.

I am delighted to be associated with the work of the charity and congratulate everyone involved over the past ten years. I look forward another decade of success.

Baroness Browning
Patron, Research Autism
WELCOME FROM THE CHAIRMAN

When I was invited by the National Autistic Society to set up the Interventions in Autism Research Trust, as Research Autism was then known, a little over ten years ago, I was extremely conscious of a profound sense of expectation. Expectation that we would shed light through our research programme on quality of life issues hitherto underexplored. Expectation that we would increase awareness of the importance of investing in autism research for future generations. And expectation that autistic people and their families would, at last, have a voice in the process of what autism research should be carried out and how.

Against this backdrop of expectations were the stark realities faced by autistic people. As a lifelong disability which impairs a person’s ability to communicate and interact socially with others, many of the 700,000 people with autism in the UK face a life of isolation, disadvantage and uncertainty. And as a condition which impacts upon the whole family, autism affects nearly three million people every day.

As we embarked upon our programme of work, guided by the views of people with autism, the depth and scale of the challenges we faced became even more apparent. This was summed up succinctly at one of our conferences by Professor Christopher Gillberg, one of the world’s leading authorities on autism research for the past thirty years. He said that ironically, as more information about autism came to light, he realised how little we still actually knew about the condition.

Research Autism has spent the past decade grappling with this challenge. During that time, we have played a pivotal role in changing the landscape of research and information provision in autism – by asking the questions that aim to improve our understanding, by generating discussion and debate, and ultimately, by working to improve the well-being and quality of life of people with autism and their families. This has been a decade of discovery for both the charity and those we seek to serve.

Our founding vision, of a world in which people with autism are no longer excluded, where they and their families are able to enjoy a good quality of life, and where the disabling effects of their condition are minimised, continues to guide the work and ethos of the charity today.

In our tenth anniversary year, there is much to celebrate and to which to look forward. But although our research and information programmes are now well established, there remains so much more to do. We need to fund pioneering new research aimed at tackling stress and anxiety, developing the best models of support, and translating research into action; we need to ensure that vital information about autism treatments and therapies reaches those who desperately need it; and we need to make certain that we engender the best possible practical outcomes from research.

I would like to take this opportunity to thank all those who have contributed in one way or another to our success over the past ten years. Autistic people and their families, researchers and clinicians, Patrons, funders and others have all played an important role in helping us to reach this important milestone. We look forward to their continued support over the next ten years so that we can fulfil our mission to improve quality of life for people with autism.

Geoffrey K Maddrell
Founder Chairman
In 2004, research commissioned by the National Autistic Society, Parents Autism Campaign for Education and the Institute of Child Health showed that despite an increase in research into autism nationally and internationally, relatively little of this research focussed on interventions. The study also found that there was little agreement between researchers and people affected by autism on the priority areas for research. In the wake of these findings, and with support from the National Autistic Society, Research Autism was founded as an independent charity and launched at the home of its Research Sponsor, Cambridge University. Its purpose was to bring the interests of the research and autism communities closer together and to improve the evidence base for interventions, treatments and services.

A number of experienced and eminent individuals from the worlds of autism research, business and education supported the newly formed organisation from the outset. As a result a robust group of Trustees, scientific advisers and patrons were formed, all of whom provided active and vocal support for the charity’s mission. Fundamental to the organisation’s ethos was the central involvement and influence of people with autism across the whole organisation.

Alongside this support from individuals, Research Autism also received a number of significant grants and funding awards to enable it to begin its work.

One of the first tasks of the newly formed organisation was to conduct a survey of the membership of the National Autistic Society, comprising autistic people, parents and professionals, to seek their views on priorities for research. This early work was undertaken by founding Trustee Dr Lorna Wing and the charity’s Research Director Richard Mills, and the findings from the 8,000 responses received would go on to shape the agenda and direction for the charity during its first decade. A number of issues were identified as being important by this community including: sleep problems, bullying, adulthood, women and girls, early intervention, social inclusion and employment, challenging behaviour, self-injury, and mental health, including the effects of stress. A plea was also made for accessible and trustworthy information about the various approaches and treatments that were “out there”.

Two major early initiatives resulted from this. Firstly the setting up of an on-line information service that would describe and rate the various approaches and secondly a series of free collaborative forums to further refine the research areas identified by the survey. These forums were hosted by London South Bank University and involved autistic people, families and professionals as well as a number of organisations interested in carrying out or funding research. These in turn led to research projects that were of direct relevance to people with autism and their families.

With these building blocks in place, the organisation began the task of setting its course for the future.

“There is a desperate need for parents to know where to turn for impartial advice on the various therapies. After our son was diagnosed we would literally try everything we could lay our hands on that promised to help. We followed up leads from the internet and popular press and it seemed that many of the professionals were as much in the dark as we were. We now know that many of the things on offer were a waste of time; some little more than ‘snake oil’ treatments.”

Alex, parent of six-year-old Shaun
Our Research: What have we discovered?
With a governance structure in place, including the support of a body of eminent scientists and people with autism, the charity embarked upon a programme of research designed to meet the priorities of the autism community. The programme was set to encompass a wide array of issues and cover the whole of the lifespan, from early childhood to adulthood. The charity began at the beginning, by focussing on early intervention.

Early Intervention
This research was conducted by a team from the University of Southampton and assessed the effect of early intensive behavioural intervention (EIBI) for autism. EIBI is a comprehensive form of intervention, in which pre-school children are taught a wide range of skills by a specially trained group of teachers, normally including the parents of the children. The two year intervention took place in the homes of children with autism in various locations in Southern England. It examined how EIBI affected their skills and abilities and, just as importantly, how their parents fared. The study was uniquely designed as a test of whether EIBI for children with autism is beneficial in routine use in the UK when compared with standard pre-school provision.

Relative to standard provision, the positive changes following EIBI included significant improvements in intelligence, language and daily living skills. EIBI also led to other significant, but less robust, improvements in motor skills, social skills and early social communication. This study statistically identified reliable change for individual children, demonstrating that 26% of those receiving EIBI showed very substantial improvements in IQ and none showed equivalent regression.

This project suggested that EIBI can be an effective and practical intervention for pre-school children with autism in the UK. It also showed that EIBI can lead to a number of significant improvements in children’s capacities without negatively affecting the psychological wellbeing of their parents.

Bullying in Schools
A key early issue identified as a priority by the autism community was bullying, and in particular how to address the high rates of bullying amongst children in secondary school.

A symposium on the topic was led by Research Autism, with input from researchers at the Universities of Sheffield and Manchester. This resulted in the development of a research study, carried out by a team from the University of Sheffield, to establish the size and nature of the problems of bullying of pupils with Asperger syndrome or high functioning autism in UK secondary schools, and ideas for identifying risk and prevention. The study set out to identify whether pupils with Asperger syndrome or high functioning autism in mainstream secondary schools were bullied more than other pupils and if so, in what ways.

The study, published in 2008, found that mainstream secondary school pupils with Asperger syndrome or high functioning autism were more isolated and more likely to be bullied than other pupils, with 90% reporting that they had been bullied, compared to 56% of other pupils. Additional data suggested that as a consequence of bullying, students with Asperger syndrome or high functioning autism led more sedentary lives. This means they are also at greater risk of obesity and associated health problems as well as long term mental health disorders particularly anxiety and depression.
This project provided important information about the prevalence and form of bullying of pupils with Asperger syndrome in secondary schools. This will help schools identify the circumstances around bullying of students with Asperger syndrome or high functioning autism and a context for prevention and intervention.

**Employment**
In 2008, Research Autism was commissioned by the National Autistic Society to carry out a systematic survey of employers and employees who had previously used Prospects, its specialist employment service. The study suggested that a significant majority of employers, some 84%, were highly receptive to employing autistic people and valued their contribution, but needed support in making a ‘reasonable adjustment’. The study also found that the majority of employers (79%) felt that the Prospects service was helpful to them when employing someone with autism, and felt that such a resource should be available more widely.

As a result of this project, Research Autism, in partnership with autistic adults and businesses, founded the Access Employment project which aims to develop an online portal to support both people with autism and employers to make the process of employing a person with autism as successful as possible.

**Sleep Problems**
Research suggests that sleep problems affect 40% to 80% of people with autism. In a 2004 survey of the membership of the National Autistic Society in the UK, over half of the respondents reported significant sleep problems.

The ideas arising out of a Research Forum, organised and facilitated by Research Autism in 2006, triggered in a number of projects related to sleep and interventions in sleep. The first of these was the development of a database of severe sleep related issues in children with autism. Research Autism worked with the University of Keele and the National Autistic Society, to develop an online database of sleep research, completed in 2010, and designed to provide support and information to autistic people, clinicians, researchers and parents. This project led to a greater understanding of the character and prevalence of sleep problems in individuals with autism. The Research Forum also highlighted a number of key areas that warranted further research in order to further knowledge and understanding in this important area.

A second project, Snuggledown, which evaluated the effectiveness of sensory weighted blankets in mitigating sleep problems in children with autism, was developed in conjunction with Guys and St Thomas’s Hospital London. Over 60 children with autism aged between 5 and 15 years old took part in this trial. The findings, published in 2014, provide valuable data showing that the blankets made no difference to quality or length of sleep in children with autism, and we hope that this will enable parents to make more informed decisions when considering whether to invest in these products.

**Challenging Behaviour**
Behavioural problems are commonly reported in young children with autism and once established can become difficult to rectify. The sensory and communication challenges faced by children are particularly important as is the response to these challenges. Working with Guy’s and St Thomas’ Hospital, Research Autism funded a study of the prevalence, severity, impact and pervasiveness of a wide range of emotional and behaviour problems in a representative clinical sample of children aged 4-8 years with an autism diagnosis.

The study, conducted from 2009 to 2011, developed and tested parent and teacher questionnaires. These questionnaires are likely to provide clinicians with a valuable framework for the early recognition and treatment of challenging behaviours in young children with autism.

**Self Injury**
The issue of challenging behaviour was high on the list of priorities and of concern to people with autism, parents and family members, and clinicians alike. This was particularly focussed around self-injurious behaviours, which are commonly reported in autism. Research Autism funded a bursary to support a programme of research to be conducted in this important area over a three year period by the University of Birmingham.
The study, published in 2012, found that self-injurious behaviour was found in 50% of the sample of 149 children with autism. The study also found that the presence of self-injury was associated with significantly higher levels of impulsivity and hyperactivity, negative affect and significantly lower levels of ability and speech.

This study provides valuable information that will help practitioners understand the causes and nature of self injurious behaviours, and will help them identify potential interventions to address them.

**Caregiver Stress**

Parents of children with autism typically experience high levels of psychological distress and infrequent respite from their caregiver role, allowing them little time to seek help for themselves let alone to participate in research. In 2012, Research Autism commissioned a project with a research team at the School of Life Sciences at Northumbria University on a project which evaluated whether a home-based intervention, involving a writing exercise focussing on the positive experiences associated with a stressful situation that had been shown promise with other groups of carers, had potential to provide an adaptable and cost-effective stress-reducing intervention for parent carers of children with autism we were keen to be involved.

The findings of the project were promising, in that caregivers who had high levels of distress at the beginning of the project and who used the intervention, saw an improvement in their mental health at the end of the project, indicating that a home-based written benefit finding exercise might be an effective intervention for this group. The study also demonstrated that further work is needed in this area in order to find ways of adapting this intervention so as to increase its effectiveness among carers of children with autism.

**Re-Mapping Autism Research in the UK: Identifying Priorities for the Decade Ahead**

Nearly ten years after the findings of the first Mapping Research Project were published, a major follow up study commissioned by Research Autism was carried out by the Institute of Education and Institute of Psychiatry. The study, published in 2013, confirmed that the UK lags behind some other countries, with the average research spend per autistic individual being 18 times higher in the US than in the UK. Furthermore, more than half of all autism research published and funded in the UK is devoted to understanding more about the underlying biology, brain and cognition of autistic people. Comparatively little research in the UK had been conducted on diagnosis, treatments and interventions, services, and societal issues. Research Autism and the authors of the study called for this imbalance to be redressed.

The study also highlighted that the divergence in priorities between the research and autism communities, which had been identified in the original mapping study, continued to exist. The study therefore gave a particular emphasis to the views of autistic people in the recommendations and priorities. The report has been extensively referenced in policy across the UK and its impact will likely be felt for many years to come. It has also informed Research Autism’s own priorities for the next phase of research.

**Mentoring**

In 2007, Research Autism held a Research Forum on the theme of ‘Successful Futures for Adults with Autism’. At this Forum, individuals with autism highlighted concerns around employment and life skills, and a key message was that existing models of support were inappropriate and failed to meet their needs. Those present articulated the need for access to a specialised, time-limited mentoring service that may be in addition to, or instead of family or other forms of support. In 2008, Research Autism facilitated and funded the establishment of a scoping group of adults with Asperger syndrome and high functioning autism, to design an autism-specific mentoring scheme with the assistance of the Autism Centre at Sheffield Hallam University. This scoping group developed the brief, and a name for the project, Cygnet, and proposed the establishment and evaluation of the impact of a mentoring scheme.

In 2014, the Cygnet mentoring research project was launched, implemented by the University of Cambridge and London South Bank University. Findings of the project will be available in 2016.
A Google search of the term ‘autism interventions’ produces a listing of around 17 million entries. Whilst some of these entries simply aim to provide information about autism, such a search also brings up information about a bewildering array of services, treatments, therapies and approaches that purport to improve or even ‘cure’ the condition.

The unregulated nature of the internet means that many of the claims made online about autism and autism interventions are false, misleading, or biased due to commercial or ideological influences. We know of so called ‘interventions’ that are being promoted as miracle cures for autism but which amount to little more than ingesting bleach-like substances, some that involve the application of electric shocks, and others still which require autistic individuals to be wrapped in wet, ice-cold blankets for prolonged periods of time.

Easy access to impartial information is therefore vital to enable people with autism and their families to make informed choices about the interventions they use, and to avoid investing time and money in those that may be ineffective or even dangerous. When Research Autism was founded ten years ago, one of its first tasks was to tackle the vacuum that existed in relation to reliable and impartial information about treatments and therapies for autism.

**Website**

In 2005, preliminary work began on the development of a website that aimed to address this challenge. Boston Consulting Group provided significant input and support in the early development of the project. In April 2006, an Information Manager was recruited to work closely with Research Autism’s body of scientific advisers to establish the website. Little did they know at the time that the website that was initially created, would go on to become a comprehensive and internationally acclaimed information service, now one of the biggest, most up-to-date and reliable sites for information about autism interventions in the world.

Today, the site contains detailed information about some of the most commonly used, newly emerging and promising interventions. It also lists some of the most controversial, including those with little or no scientific validity, or those which may even be harmful. Interventions are given a ranking based on the quality of evidence available and the opinions expressed are impartial and free of bias from sponsorship or affiliation with any approach or organisation. Since it was set up, the site has grown and demand for the information it carries has increased, with around 20,000 people visiting the site each month.

In addition, the site also houses a vast library of research publications as well as news about Research Autism’s own activities and research programme.

In 2013 Research Autism was awarded the NHS Information Standard, a certification scheme for health and social care information that has been established by the Department of Health to help patients and the public make informed choices about their lifestyle, and their options for treatment and care. Research Autism was the first autism charity in the UK to receive this certification which verifies that the information it produces is accurate, accessible, impartial, balanced and evidence-based.
Over the past two years, Research Autism has expanded its online provision to include greater use of social media to widen the reach of its information. 2013 saw the launch of a successful programme of online Q&A’s with a wide range of experts in the field, enabling people to ask the questions that were most important to them. To date, nearly 3,000 people worldwide have been engaged in them.

The Lorna Wing Conference Series
In 2010, Research Autism launched the Lorna Wing Conference Series, named after one of the charity’s founding Trustees and a pioneer in the field of autism. As well as giving her name to the conference series, Lorna was an active contributor to their content and development before her death in 2014. She also chaired all of the early conferences, the first of which was entitled ‘Autism in Women and Girls’, and attracted participants from as far afield as Turkey and Japan.

The conferences have been a unique opportunity to bring together people with autism, family members/carers, clinicians, researchers and professionals to discuss the latest research and developments in autism. Over the years the conference programme has grown, addressing a diverse range of topics including challenging behaviour, stress and anxiety, co-morbidities, and the impact of computer technology on the autism community.

Publications
Over the years, Research Autism has also produced a number of research-based publications, the aim of which has been to convey sometimes complex, scientific information to a lay audience. The Research Reports series outlines the main findings of the organisation’s research projects, whilst the newer Research Reviews focus on a particular themed topic such as sleep and challenging behaviour. All publications aim to provide people with autism, family members/carers and those who work with them, with practical and evidence-based information about autism interventions. All of these publications are also freely available to download from Research Autism’s the website.

“This website is a gem for parents looking for up-to-date, practical information on where to start tackling autism or what else to consider along the challenging journey of treatments and interventions. It is balanced, comprehensive and thorough; an amazing resource that will help many families navigate through the minefield of information available. A big thank you to the Research Autism team”.

Carmen King

“What I like about Research Autism is that you are impartial. Knowing there is no political slant or vested interest to what you do is incredibly valuable, and in many ways, unique. The fact that there is somewhere so informative and encyclopaedic to signpost professionals such as my GP onto is very reassuring and makes me feel more likely to be taken seriously. Research Autism appeals to and informs a wide range of audiences on what can still be a very misunderstood spectrum”.

Sam Rospiglisi

94% of users found the information on the website useful

71% of users said a visit to the site increased their confidence or ability in making informed decisions on interventions.
During our first decade, Research Autism has made a significant impact on the autism landscape in the UK. Our research and information programmes have helped to secure better outcomes for people with autism and their families. Yet ten years on, the need for our work remains as urgent as ever.

As more and more children and adults are diagnosed, and as the first generation of adults with an autism diagnosis grow older, we need better services to meet their needs. As professionals struggle to cope with increased demand and decreased resources, we need to ensure that they are equipped with the best possible information about evidence-based treatments and therapies. We aim to address these pressing areas of concern over the next five years through the following strategic priorities:

**Stress and anxiety**
When not addressed, stress can destroy family life, undermine employment and life prospects, and lead to additional behavioural, psychiatric and physical health disorders, at a vast cost to the public purse. We plan a programme of research through which we will identify the most effective interventions for stress reduction.

**Models of care, education and support**
Autistic children are still more likely to be excluded from school than any other group, and many adults lead restricted lives in institutions or segregated residential settings, or even find their way into the criminal justice system. This programme of research will identify the interventions that are most effective in making a positive difference.

**Translating research into practice**
There is a pressing need to understand how positive outcomes for people with autism that are founded in research can be achieved in the real world. Our research programme will focus on how research projects are designed and disseminated. Priorities to be addressed in this area will include how existing health interventions might be useful in autism if effectively modified.

**Widening the reach of our information service**
We aim to widen the reach and impact of the information service in the coming years through a number of initiatives. This includes working closely with the Royal College of General Practitioners to deliver their autism clinical priority programme over the next three years, in order to raise awareness amongst GPs.

**Developing tangible outcomes from credible research**
We will develop initiatives aiming to translate the findings of research into practical action, the first of which is our Access Employment project. This aims to establish a model of support to enable the successful employment of people with autism. Future projects will emerge from our ongoing research programme.

Research has the potential to change lives by identifying and encouraging the use of interventions that are safe, evidenced and effective. At the end of our first decade, our track record and international standing put Research Autism in a prime position to drive this agenda forward. We look forward to working with a broad range of partners to deliver our aims and, ultimately, to improve the lives of people with autism and those around them.

*“By shining an objective light on the interventions that are out there, you are lifting the fog of confusion that hangs over autism.”*

Rt Hon David Cameron MP, Prime Minister
THANK YOU TO ALL OUR SUPPORTERS

The work of Research Autism over the past decade would not have been possible without the support of many individuals and organisations, for which we are extraordinarily grateful. Their generosity, encouragement and backing have been, and continue to be, essential to our development, and have enabled us to thrive and prosper for the benefit the autism community.

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Research Autism is the only UK charity dedicated to the promotion of research into non-biomedical treatments, therapies and approaches in autism. Our vision is of a world where people with autism are no longer excluded and are able to realise their full potential, where they and their families are able to enjoy a good quality of life, and where the disabling effects of their condition are minimised.

We commission, carry out and support high quality, independent, scientific research into new and existing health, education, social and other interventions. We also disseminate impartial information about autism interventions through our acclaimed website (www.researchautism.net), and seek to translate credible research into action through the development arm of our work. Research Autism is the only autism charity in the UK to have been awarded the NHS Information Standard, a rigorous certification scheme for health and social care information providers.

Research Autism remains committed to bringing together people with autism, their families, service providers and researchers in the quest for effective interventions, and we involve those personally affected by autism in all levels of our work.
HOW CAN YOU SUPPORT US

You can help make a lasting impact on the future for thousands of families living with autism.

By making a one-off or monthly donation, you can: help fund pioneering, practical research which will lead to new therapies and interventions; ensure that vital information about autism treatments and therapies reaches those who desperately need it; and, enable us to translate research into practice.

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<thead>
<tr>
<th>Cost</th>
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<tr>
<td>£25</td>
<td>Enables us to provide people with autism, family members and carers and those who work with them with a weekly bulletin on the latest news in autism</td>
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<tr>
<td>£50</td>
<td>Enables us to provide people with autism, family members and carers and those who work with them with a monthly bulletin on the latest research in autism</td>
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<tr>
<td>£115</td>
<td>Enables a person with autism or a family member/carer to hear from a researcher about their latest work at one of our conferences</td>
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<td>£300</td>
<td>Enables us to run an interactive online Q&amp;A led by an expert on a key issue or topic, giving people the opportunity to ask the questions that really matter to them</td>
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<tr>
<td>£410</td>
<td>Enables us to provide our vital information service about treatments and therapies for one day</td>
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<tr>
<td>£700</td>
<td>Enables us to develop a new information resource for people with autism and learning difficulties</td>
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<td>£1,000</td>
<td>Funds a practical guide for people with autism and parents/carers on a key issue that affects them, such as bullying, challenging behaviour and self-injury</td>
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<td>£8,000</td>
<td>Enables us to bring people with autism, family members and the professionals who support them together with researchers from across the UK at one of our conferences</td>
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<td>£55,000</td>
<td>Funds a complete one-year research project on one of a wide range of topics such as what could improve employment opportunities or educational outcomes for children with autism</td>
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Become a Friend of Research Autism and keep up to date with the very latest in autism news and research, whilst also supporting our work. Visit www.researchautism.net/become-a-friend for more information and to sign up.

If you would like to support us by making a donation on a more regular basis, then please contact us on info@researchautism.net or 020 3490 3091 for more information.

You can also undertake one of a wide range of runs and challenges that we have to offer. To find out more please contact Mary Lawrence on events@researchautism.net or 020 3490 3091.
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