Unlocking Potential through Early Intervention

An Introduction

Revolutionising how autism in young children is perceived, understood, managed & treated.
Contents

1. Foundations
   - Purpose & Activities
   - Mission
   - Goals
   - Vision
   - What is Different about This Charity
   - Values

2. The Need and Our Response
   - Early Identification
   - Effective Early Treatment
   - Guidance for Parents
   - Personal Growth for Autistic Children

3. Our Plans
   - Early Intervention
   - Mifne
   - The Hub
   - Schools Programmes

4. Organisation
   - History
   - Team
   - Organisational Structure

5. Into the Future

6. Resources

Transforming the lives of autistic children;

Empowering their parents and carers - through practical guidance and resources - to unlock their children’s true potential.

Encouraging earlier interventions, creating stronger relationships, better living environments and brighter futures.
1. Foundations

In 2010, it became clear that Daniel Shahar, aged 1, was experiencing regressive autism. Faced with no clear source of guidance, and an insistence from doctors that no conclusions could be drawn for at least a couple more years, Daniel’s parents were fortunate to come across the Mifne Clinic in Israel. Through an intensive 3-week programme of specialist and nurturing psychotherapy, his life was transformed, and his parents were trained and equipped to continue this revolutionary work in the context of their daily lives.

Unfortunately, the second part of this story is a rare occurrence, but the first is all too common.

It is now widely recognized that more than 1% of the population has autism, and that, including their families, the condition touches millions of people in the UK. Yet there is little truly meaningful practical support, guidance or treatment that is widely offered. There is little commonly accepted understanding of how autistic children experience life or what true potential lies behind the apparent “disability”.

Moreover, the average age of diagnosis is more than 4 and a half years in the UK, a figure which has not decreased for well over a decade, compared with 25-30 months in Israel. Diagnosis is usually preceded by a very long wait, often measured in years rather than months, and many parents experience that their hopes for support, direction and treatment following diagnosis turn out to be illusory.

The desire to redress all of this is the genesis of the Transforming Autism Project. Daniel Shahar’s father, Guy, is now the CEO of the charity, which he co-founded with Gilles Pelenc (now a Trustee), another father of 2 autistic boys whose lives were transformed through early intervention. Together, they resolved to change the way that autism is understood and addressed and the age at which intervention takes place, and – through this - to give young autistic children the very real prospect of a rewarding and fulfilling life that is often considered impossible, but which they knew to be available.

We are working with the Mifne Clinic in Israel, who will help us to establish our own Mifne Clinic here in the UK using the method that they developed and have tried and tested over the past 30 years to revolutionise the lives of autistic children here.

The charity became registered in the summer of 2017 and its objectives are to achieve the following:

- Empower parents to recognise the very early signs of autism and the power of Early Intervention through awareness campaigning.
- Bring our own Mifne Clinic to the UK
- Create a comprehensive portal of support, guidance and community for parents and carers of autistic children
- Begin to develop and make widely available a distinctive autism-awareness training programme for school staff and SENCOs, focusing particularly on how to practically best serve autistic children in an educational setting. Nearly one in five autistic children have been suspended or expelled from school and a high proportion experience bullying (with more than a third naming it as the primary reason for unhappiness at school). More of an understanding of how children with autism experience life at school and how it can be optimised for them in order to avoid such unnecessary and confidence-shattering personal trauma is one of our key priorities.
- In the long term, lobbying to influence public policy and the NHS to bring down the age of identification, diagnosis and appropriate treatment for children with autism.
Purpose & Activities

Mission

We empower people with autism to be recognised for, and live to, their true and full potential. We work to continually advance the public and professional understanding of autism globally.

Goals

- To revolutionise the current understanding of and approach to autism in the public, professional and policy spheres
- To promote awareness of the power of Early Intervention in autism, and to make it accessible through a Transforming Autism Mifne* clinic in the South East of England
- To provide, through a distinctive online portal, inspiration and practical support for families, schools and others to achieve a transformation in their children’s quality of life through the creation of an optimal environment and relationship with them.

* Mifne is Hebrew for “Turning Point”

Vision

We want a world where all people are valued and treated according to their inner essential humanity, rather than according to the many labels that each of us could wear (or that could be attached to us).

Our work is designed to bring the dream of such a world much closer for people with autism.
Foundations

What is Different about This Charity

The Transforming Autism Project is not just another autism charity. Our areas of focus are not readily covered by other charities, and we are truly unique in several ways:

- We have a distinctive and empowering understanding of autism and of what autistic people are capable of. This permeates all aspects of the services that we will offer. It was first introduced in our TED talk and has been expanded in our book and the many articles on our website. It has consistently been commented by autistic people that it describes their experience of life in a way that they have never before heard articulated, and that they have been moved to tears by this.

- We are proposing and facilitating identification and intervention at an extremely early stage of life, when autism is currently rarely recognised. This enables profound lifelong changes to take place that would not be possible later.

- The particular form of treatment that we propose and will offer is a pioneering, natural non-invasive therapy that has been developed and successfully delivered over the past 30 years at the Mifne Centre is Israel, and more recently in a few other Mifne Clinics around the world. It is wholly in line with our own understanding of autism, and has been demonstrated to fundamentally transform children’s lives, as this Israeli TV News report shows, but does not resemble anything currently available and affordable in the UK.

- Our online Hub will meet a gaping and surprisingly unfulfilled need for a single place where essential and very high-quality guidance is available on all aspects of life with an autistic child - thoroughly researched, constantly updated, easily navigable and accessible, compellingly presented and carefully crafted to be as comprehensive as possible while being very easy to absorb. The content will be consistently in line with our approach to autism.

- Our unique Autism Awareness Programme for Schools will bring together our understanding of autism and our approach to treating children, to empower teachers and school leaders to make meaningful changes in their schools. This will enable children at an older age to benefit from our approach and will further raise awareness of the true nature of the condition. It will also empower parents with the much needed guidance and confidence to choose the best school for their child.
Values

Unconditional Respect

- **Kindness** - Active and constant interest in each other’s welfare and how best to promote it. Unquestioning acceptance of the inherent and equal value of each person, regardless of their attributes and character.

- **Trust-based Collaboration** - True sense of team unity and keen mutual empowerment in all actions. Authenticity in our activities, intentions and feelings. Being consistently true to our word. Resilience - having the courage to keep trusting others and to honour the trust placed in us.

- **Responsivity** - Constant alertness and responsiveness to others’ needs while anticipating and being open about our own needs, treating both as equally important. Being open, constructive and considerate about any difficulties or issues, never putting on a front.

Courage

- **Pioneering Big Thinking** - Thinking outside traditional constraints to realise a belief in what is possible (and beyond). Questioning established assumptions, unafraid to modify or build from scratch to ensure efficacy and distinctiveness. Openness to unconventional goals and routes, irrespective of traditional approaches.

- **Ambition** - Uncompromising aspiration. A focus on excellence in all areas and on abundant possibilities rather than on any limitations or apparent scarcity - to allow full potential to be revealed and keenly pursued.

- **Perspectives, Not Positions** - Approaching issues and decisions not with fixed opinions that we then need to defend, but rather with perspectives on what seems to us to make sense, to enrich and be enriched by others’ perspectives.

Purpose

- **Positive Approach** - A firm focus on the positives of any situation rather than what’s difficult; and on what we can achieve rather than what we can’t, overcoming any obstacles along the way.

- **Ownership** - Firmly owning each activity we are engaged in, and determinedly seeing it through to the end, keeping others informed and carrying them with us. Seeing the charity as ours, and feeling a wish to contribute in a variety of ways.

- **Continuous Learning & Improvement** - Actively seeking and implementing the lessons to be learnt from all our daily activities and experiences, in the enthusiastic pursuit of excellence in all areas.
2. The Need and Our Response

1 - The Early Signs of Autism are rarely acknowledged

It is common for parents’ instincts that there is something different about their child to be dismissed when they seek medical guidance, and for them to be told that the child is too young to worry about autism. Many months, and often years, can pass between a parent’s first approach to a doctor and autism assessment and diagnosis.

As a result, the opportunity to address any difficulties associated with a child’s autism during the formative years - when meaningful, long term life-altering changes can be achieved - is irretrievably lost.

Our Response - Awareness and Policy Work on Early Intervention

Our voice will accelerate the conversation around Early Intervention in autism, establishing the foundations for being able to force this issue higher up the policy agenda.

We will empower parents by equipping them with a meaningful understanding of autism, of how it can be detected early, of how they can work towards an early diagnosis and real help.

An awareness campaign will leverage support from the professional community to validate parental concerns and influence public policy on autism.

“It is about delivering trust, self-belief, confidence and love to the child”
2 - There is little effective treatment available in the early years

Even in those few cases where problems are acknowledged early (usually only the most severe ones), there is little help available to parents that wish to naturally bring out the best in their child, beyond under-resourced speech & language or occupational therapy sessions, limited both in their access and their efficiency. In some cases, drugs are even prescribed – potentially creating a lifelong dependency with no regard to side-effects or to ways of naturally bringing out the best in each child.

So, even where the difficulties are acknowledged, parents are offered no real means of improving their children’s quality of life. So, the opportunities for meaningful, long-term, life-altering changes are - even when the difficulties are acknowledged - still irretrievably lost.

Our Response: A specialist early intervention clinic to permanently transform the quality of life of young autistic children.

We will open a Clinic to treat very young autistic children using the pioneering and transformative Mifne method, as developed over 30 years at the Mifne Center in Israel.

This powerful method involves first creating a calm, safe and interesting environment around the child, and then playing with them in a particular way that evokes their natural interest in interacting with the world and with other people, from which they start to derive fulfilment.

It is about delivering trust, self-belief, confidence and love to the child to fortify them throughout their future life and give them the inner-strength to manage themselves and negotiate the world.

It is also about thoroughly training the parents to maintain both the therapy and the daily behaviour towards their children that they learn during their visit, integrating these into their lives to sustain and enhance the benefits of the treatment so the child receives maximum and permanent benefit. Long-term remote support will be provided to the parents.

One family is treated at a time, and the full resources of the clinic are focused on and geared towards the specific individual circumstances and requirements of their situation. As a result, the effectiveness of the treatment is unmatched.

Our book, Transforming Autism, describes this method in detail through the story of our CEO’s experience at the Israeli clinic with his son.

Methods that treat autism at such an early age (below 2) are extremely rare, and typically prohibitively expensive, due to their intensive and dedicated nature. We plan to charge families according to their means, and for the balance to be met through our fundraising efforts. The precise mechanism for the calculations will be decided at a later date, but well in advance of the opening of the clinic.
While there will be relatively few families (15-16) treated per year at the clinic, the work that the clinic does will still have tremendous social impact in the following ways:

- By treating the child so thoroughly, so individually and so sustainably at such an early age, the transformation of their lives becomes genuinely phenomenal. This video from Israel TV news - following a family who visited the clinic there - testifies to the sort of changes that are possible even during the initial treatment. When the methods are integrated into daily life following treatment, these are further significantly enhanced;

- As a result, children who were heading for a life of dependency and frustration can now expect an independent and hugely fulfilling life;

- From a financial point of view, the person will no longer need to claim disability benefits or to draw on social services. This will more than cover the apparently high cost of the treatment within just a few years, and the money saved in this regard for the rest of their lives (not to mention the taxes they will pay on earnings that they could otherwise never hope to earn) will contribute to the national finances.

- From a societal point of view, the person will able to make bring their unique skills and qualities - which would otherwise remain concealed behind a life dominated by anxiety and frustration – to bear for the benefit of all.

- Every family who receives treatment in the clinic is living evidence of the fact that a child with autism – even of a “severe” nature – can, if the right treatment is received early enough, live a complete and fully integrated life. Combined with our awareness campaigning and subsequent policy work, we intend that this this will have a profound impact on the prevailing understanding of how autism is perceived and treated (as it has done in Israel, where, for example, the average age of autism diagnosis has reduced from 4.5 to 1.5 years since the first Mifne Centre opened there).

So despite the numbers – which are necessarily low due to the profound nature of the treatment - the social impact of the clinic and of each treatment will be immense. None of this could be achieved in a clinic that dealt with a greater number of families at a time.

“We will create a much needed online “Hub” that provides this navigation in a single, clear one-stop portal”
3 - There is little comprehensive guidance for parents after diagnosis

After an often hard-fought diagnosis, parents are typically briefed in the “symptoms” of autism, given generic techniques to manage them and pointed to various support groups to talk about them further and perhaps learn some coping strategies from peers. They may be advised that - if they are very lucky - they might find some alternative therapy, like osteopathy, homeopathy or a dietary intervention, which might partially alleviate some aspects of the condition, though it is stressed that the results are likely to be modest and they do not work for everyone. Anyway, none is recommended as they fall outside the remit of the “professionals”, meaning support in accessing these treatments is often limited and expensive.

As a result, parents are often lost in the wilds of the Internet - with its competing advice, its dubious claims & stories of miracle “cures” and its merciless marketing - with no way to navigate or make sense of it.

And this at the same time as needing to learn to negotiate their way through complex and bureaucratic relationships with the educational, welfare and medical services.

Our Response - A portal of comprehensive support for parents and carers at any stage of bringing up an autistic child

We will create a much needed online “Hub” that provides easy navigation through all aspects of what is required to successfully bring up an autistic child, in a single, clear one-stop portal.

It will include the basics of how to begin orienting ourselves in all we need to do to support our child (including a first 30-day tool-kit), guidance on working with the authorities (e.g. health, education, social services, benefits agencies), support on managing various behavioural issues and a clear and simple guide to the various therapies available and families’ experience of them.

It will also include an interactive element, where members can sign in to comment, rate content, share their experiences of, for example, a therapy being described and contribute to the ongoing development of the portal.

Two of the design principles for The Hub are “Less is More” and “Everything is Exceptional”. We will avoid overwhelming the user with information and ensure that we effective and comprehensive coverage in simple text, tables, infographics, other visuals, interviews, videos, checklists, worksheets and more. Moreover, we will feature original contributions (including videos, interviews and other resources) from autism specialists, founders or prominent proponents of each therapy, advocates, and many more.

We will also develop original content and applications to complement the information and resources. We have already created and made available, in association with Professor Simon Baron-Cohen of Cambridge University, our first web-app for parents to complete his well-respected Q-CHAT questionnaire to detect the early signs of autism in toddlers.

Care will be taken to make The Hub as easily navigable and usable as possible, as this is a top priority. Our intention is to hold parents’ hands (the third design principle) as they are guided through their particular story, creating experts of each parent while requiring the minimum of exertion from them (the fourth). We want this portal to be regarded as the definitive support resource for parents of autistic children, and will continually update and expand it over the long term, ensuring it remains a valuable and dynamic resource, and is known as such.
There is little opportunity for personal growth for autistic children

We know that once an autistic child’s essence is acknowledged and nurtured, there is huge scope for that child to prosper and bring their best qualities to light. Unfortunately, the overwhelming majority of educational provision, even in good quality special schools, may at best provide the child with the safe environment that they need, but do little to meaningfully reduce their dependence on that environment for the long term. We all need opportunities for personal expansion and there is no reason to deny these to autistic children, beyond an incorrect assumption that they are not capable of such expansion.

Our Response – Training for Schools

We will begin developing specific training programmes for the staff and leadership of mainstream and special schools on the following:

1. How we really understand autism in children
2. How to create the most nurturing physical and emotional environment for autistic children
3. (for mainstream) How approaches to managing autistic children may differ from those for non-autistic children.
4. Uniquely, how it is possible to optimise opportunities for personal growth and expansion for autistic children so that they may transcend their generally accepted limitations in the most rewarding and esteem-building way possible.

In itself, this could revolutionise opportunities for autistic children to lead happy, fulfilled and balanced lives as they grow. What we learn through this process will also form the basis of our own education-providing activities that will come into play at a later date.
3. Our Plans

Early Intervention
A full long-term awareness campaign will be launched and will focus on the possibilities associated with Early Identification of and Intervention in autism, with an emphasis on empowering parents and carers to identify and then address the early signs of autism in their children.

The campaigns will leverage professional-led content and parent success stories to demonstrate the potential transformative results.

Our activities will include the following:

- web-based material
- videos and interviews
- social media campaigns
- traditional media
- thought-leadership at industry events
- materials and networking to lay the foundations for our later activities of influencing public policy on autism

They will also draw attention to important issues that parents and carers may benefit from understanding, for example peer and professional pressure they may experience to wait and see rather than take early action for their child, and the differences between how autism often manifests between boys and girls.
1. Procuring and preparing a suitable building
We are currently looking for a suitable building for the clinic. We are in the process of approaching a number of councils in the South East of England with our building brief, with a view to securing a long-term lease at as low a cost as possible.

This is a prerequisite to the final selection of clinic therapists, who will need to know the final location of their prospective workplace, and to the reservation of training slots for the specialist training of these therapists at the Mifne Clinic in Israel.

This building will then need extensive renovation in order to be fit for clinical use for our purposes. This will take place in parallel with the therapists’ training – which is likely to take several months to complete – so that both the clinic and the therapists are ready at the same time.

Permanent clinic leadership and administrative staff for the clinic will then be appointed.

2. Sourcing and training the therapists who will work there
Once a building is secured and in parallel with the preparations for its use, our focus will be on reaching into the community of professional child psychotherapists and child psychologists to find approximately 30-35 of them who are seriously interested in working in our clinic, from which we will select 10 to be appointed and trained to work in the clinic (including 2 senior therapists and a Clinic Director). Selection will be with the assistance of the Director and senior staff of Israel's Mifne Clinic at a special 3-day selection seminar.

We will do this reaching out through our recruiters in association with our marketing team, with the support and input of the therapists already on our team, who have strong links into the child psychotherapy community.

These therapists will then be sent in batches to Mifne, Israel for hands-on training in how to deliver this therapy most effectively. If possible, each batch will be sent with a British family, who will go there for treatment, and they will be able to support that family on their return to the UK in advance of the opening of the clinic. Their work with the family will receive close supervision from the senior therapists at Mifne, Israel (who will also come to our clinic to lead the first treatment, as the final step in our therapists’ training).
The Hub
We will begin to generate content for the 12 core areas of The Hub as well as other resources (such as the 30-day toolkit) through our strong team of volunteer researchers, backed up by the therapists on the team, as well as the marketing team. The charity’s 2 co-founders will also be heavily involved in ensuring that the initial content conforms to our vision for The Hub.

As soon as we are able, we will begin development of a bespoke platform for The Hub that can realise this vision. Our IT team is currently scoping the feasibility of completing some or all of the architecture and front end for this through our volunteer base, and in parallel, we are investigating some much cheaper off-the-shelf platforms in case we are able to find one with the flexibility and customisability to be able to manifest what our Hub needs to be. We will continue to seek and explore such options and others in order to reduce or eliminate this significant charge.

Schools’ Programmes
We will bring both child autism and training specialists onto our team to develop a truly distinctive schools programme of autism-awareness training to teachers, SENCOs and senior staff.

This will bring together our own understanding of the real potential inherent within autistic children to lead rich and fulfilling lives, and to contribute to the world they live in.
16

4. Organisation

History
The Transforming Autism Project was conceived in October 2016 by Guy Shahar and Gilles Pelenc, both fathers of children with autism whose lives have been greatly and positively impacted by early intervention. Guy had earlier that year written a book about his experiences, with the name Transforming Autism, and went on to deliver a well-received TED talk on the subject in November. They both have backgrounds in business, with Guy having had 8 years’ Project Management experience with IBM, and Gilles having built a successful business and large team of his own selling consumer products.

The pair submitted an application to the Charity Commission for registered charity status in November 2016, which was granted in May 2017. They used the interim period to start building their team (see below). Guy has worked full-time as CEO since the start of this period, while Gilles has served as a Trustee.

Team
A decision was taken very early on to build our team in a different way to what is conventional in small charities. It had been observed that the leadership teams of many small charities were very commonly in a position of feeling constrained by the resources and support available to them, and that the demands of running the charity well were draining, solitary and often demoralising.

Learning from these observations, Transforming Autism decided to build in advance of requirements a large team of skilled, competent, committed volunteers who resonated with its core values and goals. The intention was to lay solid robust foundations to be able to cope with an anticipated rapid growth.

The team is increasing in number and set to grow significantly during the strategic period. We begin this period with approximately 30 volunteers, most of whom are accomplished professionals in their respective fields and fully aligned with our purpose and values. This is likely to have at least doubled by the end of the period.

The organisational structure follows on the next page and is designed to ensure that each member of the team has a strong support structure in place. Additionally, each team is envisaged to have 2 co-leads rather than a single team lead (we have already implemented this in our External Affairs team). This strategy is intended to mitigate the likelihood of a higher turnover of personnel in a volunteer organisation.

We have the beginnings of a strong Volunteer Management team to ensure and maintain positive motivation amongst our volunteers, and a strong specialist in Organisational Development specialist, who is working to further embed our values into the culture and daily life of the charity.

The current full team list can be viewed at https://transformingautism.org/team. Additionally, we are receiving pro-bono support from a range of organisations to increase or supplement the range of skills available to us.
Organisational Structure
5. Into the Future

Our Mifne Clinic
For the first 3 years of its operation, there will be one clinic in one location. This will be to consolidate our operation and to get to a point where the staff feel extremely comfortable with the method, and to give it a chance to become more widely known.

In 10 years from now, we aspire to have multiple clinics across the UK working to the same method whose therapists will be trained by those at our first clinic, which will have its own training centre. We will be recognised as a pioneer in transformative care for infants with autism to give them renewed lives.

We will see our method being widely recognised – by the relevant sections of the general public and by thought leaders and policy makers alike – as best practice, and something to emulate, including incorporating elements of it into NHS and Local Authority provision. We will be active in the influence of public health policy relating to autism, and our voice will be respected and enhanced by the living proof of the effectiveness of the treatment we are providing. We will have conducted or commissioned research to demonstrate this.

Our Hub
The Hub will also be widely recognised as an immensely valuable resource, and parents will wonder how other families used to survive without it. It will be recognised as a definitive example of a community resource containing a wealth of invaluable information and experience in a format that is extremely easy to use and to quickly find and absorb what is being sought.

The community elements of the Hub will have been enhanced in many ways, including a facility for live chat.

The content will be continually reviewed, updated, rejuvenated and expanded to ensure it is a dynamic and relevant resource at all times.

Its target audience will have been expanded, and it will be commonly used by others such as medical professionals, who will also have their own section on it.

It will go hand in hand with the production of new original content and awareness campaigning, which will remain one of our key activities.
Our Schools’ Programmes
Our distinctive approach to autism (as introduced in our TED talk), and the Mifne Method that it supports, will form the basis of a truly different and valuable autism awareness programme for schools. It will encourage teachers and leaders to understand the true potential of the autistic children in their care, and will be structured and paced in such a way that real application of what is learnt is required.

Once this is established, we will look to create an accreditation scheme in which both mainstream and special schools that have undergone this programme and claim to be implementing its principles can be regularly inspected by us to ensure that the standards are maintained and to give parents the reassurance that the setting they have chosen is appropriate for their child.

This will be a further means of making parents’ lives easier and helping them not to feel alone in their quest to look after their children, as is currently so much the case.

Our Own Specialist Education Provision
We will look to establish our first pre-school nursery drawing heavily on the principles of the Mifne Method. It will be a setting where the best in each child can be elicited, and which will be an optimal environment for children who have been through the Mifne clinic.

It may well form the basis of an all-through school that we could look to establishing at a later date.
6. Resources

Please click on the links to visit resource online:

- Our TED Talk

- Our website:
  - http://transformingautism.org

- Transforming Autism – The Book
  - https://transformingautism.org/books/

- Articles by Transforming Autism
  - https://transformingautism.org/articles/

- Early Intervention
  - https://transformingautism.org/early-intervention/

- Interviews with Autism Specialists
  - https://transformingautism.org/interviews-early/

- Make a Donation
  - https://transformingautism.org/donate/

- Our Facebook page
  - https://www.facebook.com/
    transformingautismuk/
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