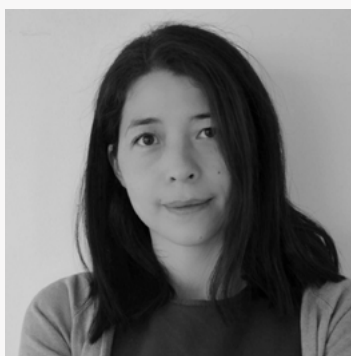




National Survivor
User Network

Annual Report 2019-2020

We are here to make sure the voice
of experience is heard





CEO, NSUN
Akiko Hart

I started as CEO of NSUN in January 2020. Last year, Sarah wrote about how NSUN brings together the past, present and future of survivor knowledge and action. This seems to me to be the key to NSUN. In this Annual Report, we honour the past through a tribute to groundbreaking activist and researcher Jan Wallcraft whose thinking was a vital part of NSUN's birth. We also reflect on present campaigns and activities, and look to the future.

We are in a time of transition and crisis. Over the past 10 years, too many people have been left behind, and change is not happening quickly enough. Within mental health, user-led groups have been decimated over the last decade. Punitive welfare policies threaten the dignity and survival of those most in need. Cuts have meant too many cannot access services when they need them- and those who can still encounter neglect and abuse. And throughout, confusingly, there has been an increasing focus on service user engagement and co-production in mental health research, policy and practice.

I have been struck by how the NSUN membership is defined by doing: whether that's campaigning, activism, mutual aid, coffee mornings, peer support. NSUN is people living with mental ill health, distress or trauma, creating community and doing things. NSUN exists to support people doing the work - through amplifying their voices and campaigns, connecting or networking them, providing direct support such as micro-grants, and

offering indirect support, which might be resources or mentoring. We need to make the case for community-led and user-led work to be understood, valued, supported and funded. We need to show policy makers and funders how it is different- and also that it cannot always replace other types of support or services.

The Covid-19 crisis has highlighted and exacerbated existing inequalities. And yet, we have also seen an explosion of mutual aid, community action and peer support across the country. There is growing interest from funders, policy makers and practitioners in grassroots, community-based activities, and in work shaped by and led by lived experience.

Diversity is key to NSUN: not one voice, but many voices. We don't just talk about mental health, because mental health isn't a thing that exists on its own, outside of people's lives. We need to think about how we best capture that diversity, across different ages and different regions, reflecting how the realities and complexities of our identities and experiences shape our lives and our activism.

Before I started at NSUN, I hadn't realised we had a seat at so many policy tables. Being invited to the table is the first hurdle- being listened to is another. There is no voice like NSUN's in national mental health policy discussions. We are needed. We are a disruptive force, and we bring to the table collective survivor knowledge. But the challenge for NSUN is to articulate an offer: what are we for, as well as what are we against?

"There is no voice like NSUN's in national mental health policy discussions. We are needed. We are a disruptive force, and we bring to the table collective survivor knowledge. But the challenge for NSUN is to articulate an offer: what are we for, as well as what are we against?"

Thank you to our members for your support- and I look forward to connecting with many more of you over the next year. Thank you to Zoe, who as many of you know, makes NSUN happen in every way, and is a joy to work alongside- and thank you to our wonderful Associates, who bring their expertise and passion to the work.

Finally, a huge and personal thank you to Sarah, for your warmth, wisdom, patience and generosity- none of this would be possible without you. ●



Former Managing Director, NSUN
Sarah Yiannoullou

NSUN has been a huge part of my life over the last 10 years. It's been a position and experience that I've deeply valued. I met and worked with so many inspirational people that I've learnt a great deal from.

Being part of a growing network and surviving some difficult times has taken a particular amount of emotional labour and that's not always easy to walk away from. But it's definitely been the resilience, passion and solidarity of the membership that has kept me close and determined to see the network continue into the next decade and beyond.

During my time at NSUN I've battled with my mania, paranoia and the subsequent burnout, but the highs and lows have been tempered by some of the most unwavering support I've ever experienced and which I'll never forget. There are way too many highlights to list but of course there are some things I have to mention, such as the widening use of the 4Pi Involvement standards, securing a place on the Independent Mental Health Act Review Advisory Panel, influencing the CQC Mental Health Act report, producing and promoting the Members' Manifesto and securing a further three years funding.

We're now facing one of the most significant periods of our personal and political lives. The solidarity of collectives such as NSUN is needed now more than ever. There is no other organisation that has taken on the responsibility of protecting and promoting our forgotten and ignored stories of the past; the challenges

"The solidarity of collectives such as NSUN is needed now more than ever. There is no other organisation that has taken on the responsibility of protecting and promoting our forgotten and ignored stories of the past; the challenges and opportunities of the present; and the potential for the future."

and opportunities of the present; and the potential for the future.

Over the last five years I've witnessed the 'quietening' of the collective, independent and direct voice. The value of user-led organisations and initiatives is not recognised in the same way as it was 10 years ago. This has been influenced by the appropriation of language; the move away from independent voice in Patient and Public Involvement; the political policies of austerity and cuts and the lack of accessible funding sources for smaller organisations.

It's only user-led collectives that will challenge this loss, that will fight to be heard and fight the injustice that we experience as individuals and collectively. NSUN has worked to sustain and strengthen our collective political voice over the last 10 years and I'm confident that it will be around to continue to do so over the next 10.

It's a long goodbye but as Winnie the Pooh said "How lucky am I to have something that makes saying goodbye so hard." ●

MEMBERS' MANIFESTO

We aim to:

1. Campaign against the injustice and harm caused by cuts to public funding and welfare benefits.
2. Challenge the abuse and coercion that continues under mental health legislation and work to ensure that people understand and can enforce their rights under the UNCRPD.
3. Actively promote the need to work with us in decisions about strategy, commissioning and how services are provided, as well as the need for services to be user-led.
4. Challenge personal, institutional and structural inequalities, injustices, disadvantages and discrimination for everyone with experience of mental distress/trauma.
5. Promote informed choice so that people are in a position to understand their difficulties in whatever way they choose and to access the support that they find best.
6. Promote the validity of survivor knowledge and research. ●



Interim Chair, NSUN
Angela Newton

I have worked with and alongside NSUN for many years, so it was with great pleasure and pride that I took up the role of Chair during late 2019-2020.

The work of NSUN is more important now than ever before and the strong foundations of its creation and development have been testament to those who have worked tirelessly since its creation. During the year, we have said a fond goodbye to Sarah Yiannoullou after she spent 10 years tirelessly and compassionately leading the work of the organisation and getting it to where it is today.

We have warmly welcomed Akiko Hart who has taken up the helm with passion, determination and conviction and we continue to benefit from the hard work, enthusiasm and approachability of Zoe Kirby to keep the show on the road. Our valuable team of Associates has continued to enable us to increase our reach and remain central to our work. We have seen some changes within our Board of Trustees and continue to strengthen our governance. I would like to thank everybody for the dedication, wisdom, insight, expertise and experience in making sure that we work on the issues that matter most to our members.

The many voices of people who experience mental distress continue to influence and inform the development, delivery and review of mental health policy and practice. They are critical to this and always will be. We continue to champion best practice within this and have spoken with a range of NHS Mental Health Trusts in addition to other

organisations to better understand how they have been able to use the 4Pi Framework in practice. We have been encouraged by what we have heard and urge others to adopt this way of working if they have not done so already.

As I write this and look to the future, I am conscious that we are living in uncertain and difficult times, and it is against this backdrop that we need to navigate our future. In the midst of a pandemic, we know that many more people are struggling with their mental health and that this brings short, medium and long term implications. We understand that our place within the mental health landscape becomes even more important and that there is an increasing need to connect us all together to demand the changes we want to see in the world. We are seeing this happen already as our membership increases, and I am excited by the prospect of doing more to ensure that we are even more accessible to those that need us the most.

We know that the coming year will be hard for many of us who live with mental distress and we are committed to platforming your views to inform, influence and change mental health policy and practice for the better. ●

4pi National Involvement Standards

4Pi is a simple framework on which to base standards for good practice, and to monitor and evaluate involvement.

The framework builds on the work and experience of many people: mental health service users and carers and others who have lived and breathed involvement.

Meaningful involvement means making a difference: it should improve services and improve the mental health, wellbeing and recovery of everyone experiencing mental distress.

PRINCIPLES

How do we relate to each other? Principles and values are the rules or beliefs that influence the way we behave, the choices we make and the way we relate to other people.

PURPOSE

Why are we involving people?
Why are we becoming involved?

PRESENCE

Who is involved?
Are the right people involved in the right places?

PROCESS

How are people involved?
How do people feel about the involvement process?

IMPACT

What difference does involvement make? How can we tell that we have made a difference? ●

Our team

Akiko Hart

CEO (from January 2020)

Sarah Yiannoullou

MD (until March 2020)

Zoe Kirby

General Manager

Soka Kapundu

Finance Manager (until March 2020)

Our trustees

Trustees who served the charity during the period were as follows:

Angela Newton

(Interim Chair, co-opted March 2020)

Helen Oldfield

(Treasurer)

Dawn Willis

(Secretary)

Zoe Bennett

(elected October 2019)

Alisdair Cameron

Eleni Chambers

Joe Kelly

(resigned October 2019)

Nick Kennedy

(co-opted October 2019)

Nic Murray

(elected October 2019)

Jonathan Rackham

(co-opted October 2019)

Emily Reynolds

(elected October 2019)

Rachel Rowan Olive

(elected October 2019)

Amy Rushton

(co-opted October 2019)

Julia Smith

Mark Wood



Our associates

We have a small team of Associates who support us with specific projects.

In 2019/20, they included: **Mark Brown, Alison Faulkner, Dorothy Gould, Stephen Jeffreys, Jayasree Kalathil, Colin King, Mish Loraine, Nash Momori, Dominic Makuvachuma, Clare Ockwell, Emma Ormerod, Debbie Roberts, Kirk Teasdale and Premila Trivedi.**

Our Governance

The board is responsible for the governance and strategy of NSUN and is elected by the members. The trustees bring a mix of skills, experience and qualifications. All trustees have lived experience of mental health distress and/or service use and are mental health activists. Members are normally appointed for a renewable term of three years.

The Board meets four times a year and delegates day-to-day responsibility for the running of NSUN to the operational team. See the Scheme of Delegation.

<https://www.nsun.org.uk/Handlers/Download.ashx?IDMF=1e8511b2-e38a-4052-b7b9-a4ea4f35cc60>

The subcommittees meet to look at finance, fundraising and human resources in more detail in between Board meetings.

As a charitable company, NSUN's governing document is its Articles of Association. A fair and open recruitment process has been developed to ensure that the Board reflects both the user-led ethos of NSUN and the diversity of the wider network. Following an application and interview process, successful applicants are proposed to the membership at the annual general meeting. ●



Co-founder of NSUN
Anne Beales MBE

In 2003, service-user-led research, coordinated by Jan Wallcraft for the User Survey Steering Group and funded by the Sainsbury Centre for Mental Health, resulted in the report 'On Our Own Terms'. It urged the formation of a national network to bring individual mental health service users and groups together to encourage good practice and build the capacity of the sector. Inspired by this report, the Sainsbury Centre funded a number of meetings and a conference in London in 2005 to agree on some practical actions based on the recommendations.

A steering group organised a conference focused on how to set up a national service-user/survivor network. Funding for five years was obtained from Comic Relief and the Tudor Trust and a hosting arrangement was negotiated with the mental health charity Together: Working for Wellbeing. The network was set up to build a more united and confident mental health service-user movement. It recognises the isolation, discrimination and disadvantage experienced by mental health service-users and their needs beyond clinical treatment. A launch conference was held November 2007 in Poole. NSUN became an independent charitable company in May 2010.

"If you don't know where you came from, you don't know where your starting point is and you can't really measure where you are along the journey. There was a time when the leaders of our movement stormed stages, they printed leaflets, they broke into NHS premises actually and printed the leaflets on photocopiers without the NHS knowing, so they could hand them out."

When we became active, we were very angry, we were very disempowered and it couldn't go on but also what couldn't go on was just being angry, you had to have a vision of what was possible. Our main demand was to have a direct, independent collective voice. Collectives of us got together with tiny resources and did amazing things. In the last 10 years, against the background of austerity and decreased funding, NSUN has grown in reputation and standing. We live in a country where 39 people have just died in a container. This is not right. We see division in our society and racism, bullying and abuse are on the increase and it's not right. What is maddening is that us vulnerable people are the ones who have to put it right because no one else is putting it right. Where have we come as a society when people are just abandoned? We're still here ten years later. We still care and we still know what hurts and what works and we have the solutions and we now have to take the steps to believe in our leadership, to reach out to others who are service users and people who have lived experience and join forces with them and build a proper movement. We can push back and say we got up off our knees and we can see further than you and further than the status quo, we will be the leadership that will make the difference." ●

Extract from speech by Anne Beales MBE, Co-founder of NSUN, NSUN AGM 2019:

<https://www.nsun.org.uk/Handlers/Download.ashx?IDMF=3b460ff6-4918-41a6-96b6-033e9fc8e812>

NSUN History

- 2003** On Our Own Terms report makes a recommendation to form a national service-user/survivor network
- 2006** The 'Doing It For Ourselves' conference launches the idea of a national network and a steering group is set up to make it happen
- 2007** NSUN is launched after securing funding for five years
- 2008** NSUN is hosted by Together for Mental Wellbeing and shares accommodation with Catch-A-Fiya
- 2010** NSUN becomes an independent organisation
- 2011** NSUN holds its first annual general meeting
- 2012** NSUN secures a further three years' funding
- 2013** NSUN attracts over 2000 members
- 2014** NSUN hosts the IIMHL Service User Leadership and Peer Support festival
- 2015** The 4Pi National Involvement Standards are published and launched
- 2016** The #NSUNthrive10 campaign is launched
- 2017** NSUN increases membership to over 4500
- 2018** NSUN launches the Reigniting the Space (for BME user/survivor voice) Project
- 2019** NSUN launches the 'Value of User-led Groups' campaign.

- Increase and diversify membership to better reflect the range of user-led and community-led activities in England
- Create a membership offer based on our members' needs

- Develop and deliver a clear communications strategy
- Increase presence and profile in local and national media

- Promote and develop service-user/survivor-led research and knowledge production
- Develop and sustain the Survivor Researcher Network (SRN)
- Facilitate collective policy responses
- Continue to seek new partnerships for research funding proposals

- Consult with user-led and community-led group members to find out how we can best support members' activities
- Facilitate and support local/regional networking
- Deliver training and workshops, and create resources
- Provide hosting arrangements for user-led groups and initiatives

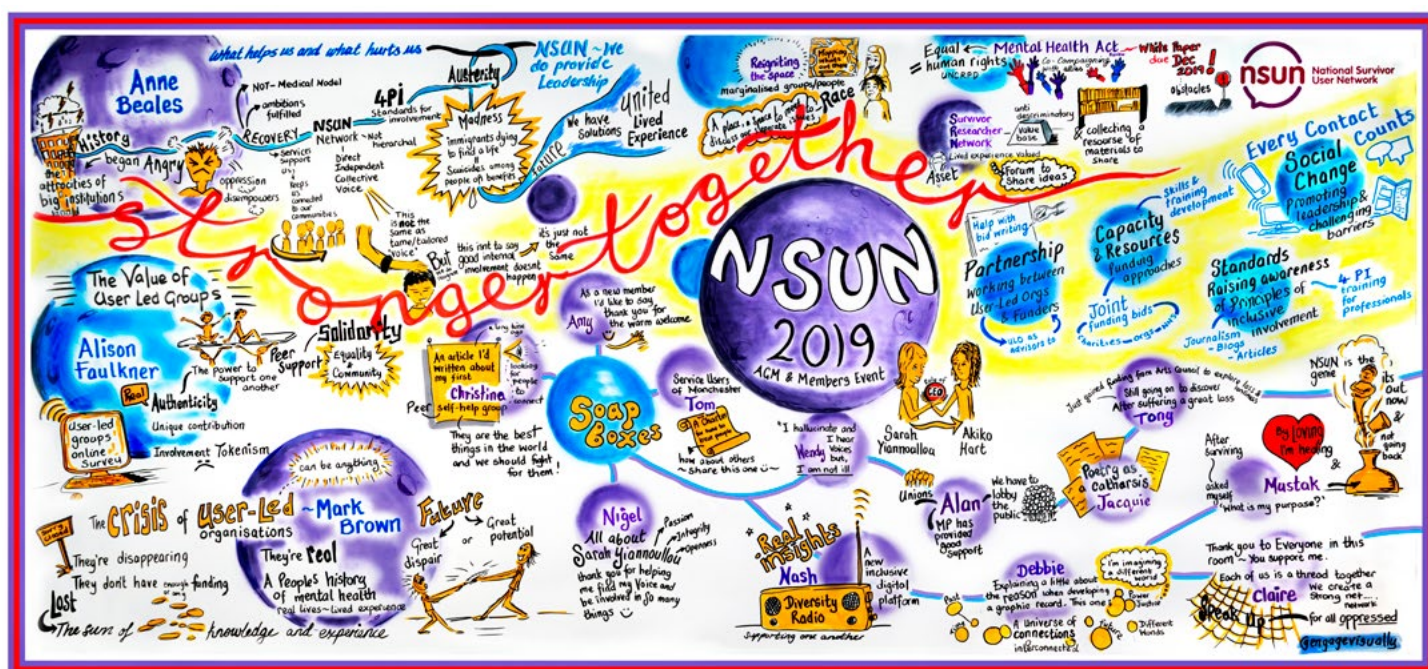
- Ensure that there is a strong user voice, at an individual, community, organisational and strategic level, including through the promotion and implementation of 4Pi involvement standards
- Support people to lead the agenda rather than respond to it
- Campaign for the authentic, independent and direct voice of lived experience

- Consolidate core and project funding through grant-making charitable trusts and contracts

Stephen Jeffreys,
Co-ordinator of the Survivor
Researcher Network

- Expand the core team
- Increase our unrestricted income
- Develop partnerships with organisations that reflect our values
- Create a membership offer
- Host user-led initiatives and projects ●

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“Dr Jan Wallcraft, who died on March 20th 2020 was an inspirational pioneer of the UK mental health survivor/ service user movement.

From the late 1980s, as a survivor activist and researcher, Jan worked collectively with a range of organisations and academics, to shape and build initiatives through which survivor/service users’ experiences and voices could transform mental health services and research. Her critique of medical models of psychiatry in mental health care and research was the basis on which she built, practically and theoretically, an approach incorporating social models of madness and distress. The body of work that she leaves behind is a stimulating resource for those interested in this field.

The School of Social Policy had the privilege of working with Jan since 2000. That year academic staff and mental health survivors/ service users who had begun to work collaboratively as researchers and educators decided to establish Suresearch - a West Midlands network of people who have used and/or survived mental health services and their allies. Its aim is to promote service user involvement in

mental health education, training and research www.suresearch.org.uk. The growing body of Jan’s published research as well as her wise advice and mentoring was nurturing to the network in its early years.

Six years later when the Centre of Excellence in Interdisciplinary Mental Health (CEIMH) was established in the School, Jan became an Honorary Research Fellow. The impact of the research teaching she undertook with both students and service users/survivors was outstanding. Her co-edited ‘Handbook of Service User Involvement in Mental Health Research’ was an invaluable resource. She was also influential in designing and delivering, with Suresearch and West Midlands mental health trusts, an NIHR funded pilot project - ‘Growing a service user and carer research resource’ (2014).

As a colleague Jan was a warm, humorous and considerate innovator who brought the best out of those she worked with. She was unwavering in her concern to build social responses to distress that positively supported survivors and service users.

In February 2020, we were delighted to renew our connection with Jan, following her previous illness, when she was reappointed as an Honorary Research Fellow to the School of Social Policy. Jan was looking at

getting her PhD on service users’ experience of crisis published and to work with colleagues on a range of projects on innovative approaches to promoting service user rights. It is a great sadness that we will not have the benefit of her wisdom and guidance moving forward.”

Emeritus Professor Ann Davis and Dr Karen Newbigging

“Jan Wallcraft was one of those survivor activists I was lucky to get to know in her different aspects as a human being. One of the problems of activism is that you can be so busy ‘struggling’ and ‘doing things’, that you never really get to know each other. I never felt that about Jan. And for me it has been one of the strengths often of the survivor movement that we have recognised we are human beings as well as part of something and people readily respect each other’s difficulties as well as strengths, the constraints our madness and distress may impose upon us, as well as our skills and abilities. Jan was someone who made it possible for you to get to know if not all, at least a lot about her, as a colleague, mother, activist – and friend. And for me that is what meaningful collective working, campaigning, learning together to make positive change is and has to be about.



► Jan was an almost constant part of my journey in the survivor movement, from my first Survivors Speak Out meeting to working on and writing up what I believe was a truly honest and helpful piece of survivor research just a few years ago on social approaches to madness and distress. I first began to get to know Jan when she was working with MINDLink and I was on the management group of Survivors Speak Out and we came regularly together. I shall always remember Jan's quiet, gentle and helpful voice. It was a time of positives and helpful collaborations. And Jan was the personification of that. And then in our last work, contributing, committed, value-based, principled and capable.

I do therefore find it very difficult to think of Jan no longer being a presence with us. I know she had in good ways taken some steps back, but she was still always a voice in my head, another positive point of reference. She still will be, but it is difficult to take in that this will no longer be literally true. But she will always be part of our history, our movement, something I am very proud to be part of and she will always be someone I am proud to have known and done good work with. Thanks Jan. We really will remember you."

Peter Beresford

"Dr Jan Wallcraft has been a permanent presence throughout my emancipatory user journey. I can remember first meeting Jan when she was invited down by my local community mental health development worker who was demonstrating that there is a whole different world to mainstream mental health services – service user involvement and empowerment. Jan came to talk to our local campaigning user group about her work and I found her quite unassuming but also very impressive. The word inspiration is sometimes overused in certain disability narratives, but Jan proved to be someone that so many of us could look up to and follow whilst she always encouraged our efforts. I got to know Jan's work and then got to know Jan, she was always accessible and friendly.

Jan was a leading light in the user movement and I was always impressed by her outputs and contributions to the debates we had. She was a generous and warm human being. Her seminal work "The Mental Health Service User Movement in England" (2003), advocated for a network of users/survivors and groups, which subsequently became NSUN. And, I can remember her mediating when NSUN was being set up, she wanted the best for everyone and

took a leadership role to show that fighting amongst ourselves wasn't going to solve anything. Always very principled Jan was a very measured touch stone for the rest of us.

Just before the COVID-19 lockdown I took on a quick piece of work for a colleague who needed very wisely to self isolate. This meant a journey to Leeds where Jan was in hospital. Although she was barely conscious she was aware that her sister Elin and I were in the room and we talked about Jan's love of Bob Dylan's music. I am so grateful that I had the opportunity to check in with Jan that last time; she was serene and comfortable, being very well cared for and loved.

We have lost someone special from the survivor movement, however Jan's contribution was enormous, and she leaves a long lasting legacy to carry on inspiring us and leading us. Thank you Jan, you are much missed but very much not forgotten.

*After I had drafted the above, I received an email from Academia.edu which is an on-line place to share and follow research. It pointed to a paper Jan had written and mentioned me in.

Thanks Jan for reaching out!"

Tina Coldham

► “I don’t remember when I first met Jan - it’s as if she was always there, whether in the background quietly working away or in the foreground, speaking out about the rights of service users and survivors. I first worked for Mind in the mid 1980s and seemed to be aware of her then. I then worked with her more than a decade later at the Mental Health Foundation when she researched and wrote the publication *Healing Minds*, on the evidence surrounding complementary therapies in mental health (published in 1998). I remember her turning up at the office with her rucksack bulging with papers, somewhat chaotic on the surface - yet writing something that exuded organisation and rigour. She went on to work with our wonderful team on the *Strategies for Living* research before taking on another role in the Mental Health Foundation. And for a while, she, Jim Read, Peter Campbell and myself formed a mutual support group meeting in our North London homes.

Somehow, Jan always maintained a sense of dignity. She was always interested in finding new and different ways of managing her mental distress, open-minded and ready to listen, and adamantly opposed to the medical model. Jan’s daughter, Sarah, described her as ‘restless’ in her eulogy, and this rings true for me. She did seem always to be searching for something - something that I think remained elusive. I remember, once, sitting in the foyer of some large hotel at a conference somewhere and having my first real conversation with her about her life and struggles. I remember my admiration on hearing that she had spent a night in prison in support of

a Ken Livingstone campaign. And I remember her brilliant writing skills - how she could reduce the word count of any document simply by removing many unnecessary words and losing nothing of the original meaning.

In recent years I saw very little of Jan. I visited her in hospital in Bristol with Mary Nettle after her first stroke, and because she appeared to recover so well, I am not sure I took it very seriously. From her Facebook posts I realised that she had not recovered as well as I thought and was affected by it until her final stroke and her death. But she continued to post with commitment and wit about politics, supporting Jeremy Corbyn as befits her lifelong socialist values. From Facebook, too, I learnt of her joy over the birth of her grandson.

It is hard to believe that one of our leading lights is gone, particularly hard for those of us who share her history. But the legacy she leaves behind is powerful and bright.”

Alison Faulkner

“I was very sad to learn that my good friend and fellow survivor Jan Wallcraft had died after a stroke in a hospital in Leeds.

Jan and I had supported each other over the years but she showed me the way most of the time. I first met her in 1987 at the Survivors Speak Out event at a youth hostel in Edale in the Peak District. I was 34 and very much a passive recipient of services and the weekend was an eye opener for me, I was never passive again! Jan had just been appointed by national Mind as coordinator of their Consumer Network, soon to be called Mindlink, she encouraged me to come to meetings as she

needed ‘consumers’ from all over England and Wales as I lived on the borders of the South West I fitted the bill. Mind at that time was based in Harley Street just off Oxford Street in central London, she felt the shopping opportunity would be a draw, as it was for her. I took up the opportunity and spent many happy times involved and much to my surprise relished the opportunity to attend and speak as a survivor at the Mind annual conferences held in seaside venues around the country.

I was encouraged by others particularly Peter Campbell and Viv Lindow and became self-employed as a mental health user consultant. With many other survivors I had started to find my voice and found I enjoyed speaking out as well as trying to get paid for it as I needed to be valued for my time.

I kept in touch with Jan and was a bit envious of her role with the World Psychiatric Association as she exhausted herself going to events around the world. I moved to Worcester at the same time as Jan and we often used to meet and occasionally work together particularly conducting survivor-led or even survivor-controlled research as we both felt it was essential to get evidence of what worked from this perspective. I could write a lot more but will stop now, it is great to share memories.”

Mary Nettle

“I first met Jan in 1983 when she was a mature student on placement at Mind - the beginning of many years of friendship and collaboration which gave me the opportunity to appreciate her great talents as a researcher and writer, her dedication

► to the survivors' movement, and her phenomenal spirit and energy.

We often travelled together, to run training days or speak at conferences. Invariably, Jan would arrive at the railway station a little out of breath, slightly panicked, possessions spilling out of an overstuffed bag. But once she began her presentation, she was always organised, assured, cool and confident.

One of my best experiences of working with Jan was writing a short series of guidelines on mental health topics to be jointly published by Mind and COHSE -The Confederation of Health Service Employees – subsequently UNISON after a merger. The project appealed to our socialist political beliefs but was fraught with difficulties. COHSE had a reputation for success in defending psychiatric nurses accused of mistreating patients. Union officials wanted to associate the union with a more enlightened approach as the old institutions closed down. But every word of these guidelines had to be approved by a COHSE committee while being consistent with Mind's policies.

The first guideline, on empowering users of mental health services (published in 1992) made quite an impact. When Jan achieved her long-held ambition of visiting Japan she was delighted to be presented with a copy of the guidelines translated into Japanese.

Jan was whole-hearted in her belief in the survivors' movement and a central figure in its progress in the UK. I remember her as always constructive, a unifier, a woman of steely determination.

Away from the world of mental

health, she was devoted to the TV detective series, Columbo, and loved Christmas and all things Christmassy.

Thank you, Jan, for enriching my and many other people's lives."

Jim Read

"I was trying to remember the first and last times I saw Jan. The first was in the late '80s in what was then South East MIND, based near Euston Station in London, where she was talking passionately about the need for non-medical crisis houses. She never gave up on that one, talking and writing in many different ways. The last time was at a BSA Mental Health Studies group in Warwick about 8 years ago. When I asked her how she was, she just said "not great", followed swiftly by her own forceful take on Foucault's The Archaeology of Knowledge. But Jan was not primarily an academic, she was an activist, organiser and thinker, all at once. And a human being who could drop human secrets in the backstage of formal events. I was quite devastated by her first stroke and amazed by her courage in re-establishing herself. And now we have lost the first of the activists of that generation, that I knew, to die naturally. It's a significant personal and collective moment and a tragedy. Peace Jan. And her own form of courage to her sisters and daughter."

Diana Rose

"Nearly twenty years ago, I sat with Jan as she wrote an obituary for a figure in the survivor movement who had passed away. Jan rarely shied away from honesty, and it was no different here. She felt that

we shouldn't airbrush people after they've passed away, transforming them into idealised saints. Whilst I admired her integrity, and her ability to write something both warm and painfully honest, secretly I hoped she wouldn't write my obituary. I never thought I would be writing this, and I find it almost impossible to do.

Jan dedicated much of her life to the survivor movement, both as a researcher and an activist. She wrote honestly about how we can be each other's worst enemies, as well as best friends, and sometimes despaired at the divisions we experience on the left of politics and activism. She taught me about the craft of writing, likening it to a sculptor who slowly chips away at the block until it comes to resemble what they are seeking. She always wrote beautifully and persuasively on some of the most important issues we face.

But Jan was more than these things – both a joy to spend time with and infuriating at times too. She was an original guilty feminist, hugely passionate about women's rights whilst waiting for her knight. She was scatty and sharp minded, fun-loving and deeply serious, empathic and always, always kind. She will be desperately missed, not just by those of us who knew and loved her, but by the wider movement. Now more than ever we need her passion, wisdom, clarity, integrity, and ability to cross divides. Our collective hearts are broken."

Angie Sweeney



Membership

NSUN continued to promote its members' activities and campaigns, including the NSUN Members' Manifesto and the Kindred Minds BME Manifesto, at every level of activity and involvement.

We supported the Manchester Users' Network's (MUN) Stepping Down campaign in February 2020, which focused on people being routinely discharged from the care of secondary services without adequate support, oversight or information to the care of their GP. The campaign was featured on BBC News North West. NSUN also reached out to its members through the weekly bulletin to build a better picture of the stepping down crisis across England, and to connect other local campaigns with MUN.

NSUN also worked on a successful campaign around peer support in February and March 2020, which was based on an Open Letter written by its members challenging the proposal of a Peer Support Apprenticeship programme, and calling for the values of peer support to be embedded across peer support work in both statutory and community settings. The Open Letter attracted over 100 signatures and was successful in galvanizing widespread support around values-based peer support.

Research

This year, we worked on the Keeping Control study, which shines a light on adult safeguarding issues and hate crime/targeted violence for mental health service users. You can read the Open Access research paper here:

<https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12806>

The findings will be turned into a leaflet for members in summer 2020.

NSUN also hosts the Survivor Researcher Network (SRN). The Network aims to provide mental health service users and survivors who are involved and interested in research with a forum for networking, sharing information and supporting each other.

SRN produces a bulletin of research opportunities, events and articles every two months. Information is also now shared via the SRN Twitter account at @SurvivorResNet.

2019/20 SRN activities include:

In June 2019, SRN prepared and presented two posters at the NADSN (National Association of Disabled Staff Networks) & LGBT+NoN (LGBT+ Network of Networks) Joint intersectionality Conference in Manchester. The posters focused on the SRN Manifesto and issues and barriers for survivor researchers in higher education.

Members of the Working Group conducted an evaluation of the 'service user and carer' involvement in a large National Institute of Health Research (NIHR) funded project 'The contribution of the voluntary sector to mental health crisis care in England' in conjunction with With-You Consultancy.

During 2019-20, a number of Working Group members have been working on a chapter exploring survivor research and barriers to involvement and progression for the forthcoming Routledge Handbook of Service User Involvement in Human Services Research and Education, edited by Peter Beresford and others.

"NSUN is important to North East together as a vital link to other user-led organisations across the country and as a great source of information on current mental health policy and its potential impact on our members."

Mish Loraine, Co-ordinator of North East Together

In 2019, two SRN Working Group members gave a presentation on the SRN and their approach to survivor research at "In the work of experience - Peer projects introduce themselves" a two-day international conference in Vienna organised by Verein LOK Leben ohne Krankenhaus (Association LOK Living without Hospital). Another member facilitated a workshop together with a Norwegian service user researcher at a critical perspectives on mental health conference in Cork, Ireland. The workshop explored identity and employment struggles associated with being a service user researcher in academia.

SRN continues to lobby research organisations and funders for opportunities for user-led research groups to apply for funding. SRN is represented at meetings of the Social Workers' Union Austerity Action Group, the Alliance of Mental Health Research Funders and the Mental Health Qualitative Research Network.

"I believe NSUN is vital to the grassroots of user-led organisations, helping to network groups with each other in an inclusive way and seeking to improve and add to our collective knowledge."

Alison Faulkner, NSUN Associate

Capacity building

We held our AGM in York in October 2019. You can read the AGM report here:

<https://www.nsun.org.uk/Handlers/Download.ashx?IDMF=3b460ff6-4918-41a6-96b6-033e9fc8e812>

We also host a range of projects and networks. (see page 15)

Involving and influencing

It's been a turbulent year, and as well as the Covid-19 crisis, and Brexit, there was also a General Election. NSUN wrote an analysis looking at what match there was between political parties' election manifestos and NSUN's 2019 manifesto:

<https://www.nsun.org.uk/news/match-between-party-political-manifestos-and-nsun-manifesto>

The Mental Health Act Review is on hold because of Covid-19. The White Paper, which will be based on the recommendations in the Independent Review of the Mental

Health Act, is due to be published in 2020. NSUN is a member of the Mental Health Alliance, which focuses on mental health legislation, and we will continue to keep members updated with any developments.

A consistent thread of NSUN work in 2019/20 has been the The Value of User-Led groups. For World Mental Health Day 2019, we spoke about the crisis user-led groups are facing and the vital role they play in supporting people through their most difficult and distressing times. We co-organised a dialogue between funders and user-led groups with Shaping our Lives and Lankelly Chase and continue to focus on the issues that the user-led groups which make up our membership face.

We've also promoted the position and voice of service users within NICE frameworks, including through the campaign on NICE guidelines for psychotherapy and depression, which has evolved into a joint project with Essex University and Shaping our Lives in 2020/21 on service-user/client choice when accessing services and support for depression.

Sustainability and influence

Through our partnership work with Mind, NSUN built on its 2018/19 work with Sussex Partnership on the Peer Support Charter, to map the full range of peer support available within Sussex, with a view to creating a directory outlining the choices available for someone living with mental ill-health or distress and who is looking for peer support. NSUN also produced two thought pieces around peer support, one on peer support and safety, and the other (alongside Mind and

How does NSUN do policy work?

NSUN is in a number of different policy groups, which helps us pick up news and developments early. It also means we can lobby decision makers directly, and form alliances with other organisations when this is useful. For example: when it comes to mental health legislation, we have worked closely with the British Institute of Human Rights and Liberty.

Some of the policy groups we're a member of include:

- the Mental Health Independent Advisory Oversight Group, which tracks progress against the NHS Long Term Plan
- Health Education England's New Roles in Mental Health: Peer Support group
- the Mental Health Alliance, which focuses on mental health legislation
- two consortia at the Health & Wellbeing Alliance at Department of Health & Social Care (the Lived Experience Alliance, formerly the Win-Win Alliance, and the Mental Health Consortia)
- the Disability Benefits Consortium, which we joined in 2020
- the Covid-19 & Mental Health Psychosocial Support Government taskforce
- and regular Care Quality Commission (CQC) meetings and updates

► the Association of Mental Health Providers) on peer support within the voluntary and community sector.

A key aim for the financial year ending 31st March 2020 was to secure core funding to enable NSUN to plan and support user-led projects and respond to unplanned opportunities and initiatives.

We're delighted to report that new core grant funding was successfully secured in the year from The Esmée Fairbairn Foundation and the Tudor Trust. We are incredibly grateful for their support. We are also grateful for the ongoing support from Trust for London, Mind, Lankelly Chase and Disability Rights UK (DHSC) for grant income to support various projects during the year.

Aims for 2020/21

In 2020/21, NSUN will review its strategy to adapt to a turbulent period which has had and will continue to have a big impact on people's mental health.

NSUN also aims to build capacity in its membership through a micro-grant making programme for User Led Organisations (ULOs), as well as a series of resources aimed at strengthening the resilience of ULOs and facilitating shared learning. We are also aiming to gain a better understanding of the sector through mapping our members' activities. We will continue to promote and amplify members' perspectives, voices and campaigns through our communications and policy work, and ensure that NSUN is a disruptive and constructive voice in policy settings, challenging the focus on individual expertise and bringing to the fore collective knowledge and action. ●

Covid-19

Covid-19 and its aftermath present a number of significant challenges for NSUN.

The wider economic consequences of lockdown will hit our members the hardest, and will change our work and our priorities. Many of our members will also face personal challenges, including shielding, bereavement or illness. Covid-19 has highlighted and heightened inequalities, and marginalised or racialised people and communities have been and will continue to be disproportionately affected.

Whilst NSUN has been successful in securing some Covid-related funding, there are a number of challenges ahead to secure core funding in what will become an increasingly competitive field. From a team perspective, NSUN were already working remotely, and so the move online has not been disruptive for the team.

From a policy perspective, the landscape has changed, and NSUN will continue to need to find a balance between responding to events, and continuing its long-standing work. Certain campaigns have been paused (for example, the refresh of the 4Pi involvement framework) or adapted (the Value of User-Led Groups campaign). We have focused on key areas where we add value and expertise. For example, in March 2020, NSUN analysed the proposed mental health changes in the Coronavirus Act and wrote

two press releases on it, covered in Disability News Service and Mental Health Today. NSUN's analysis was also picked up by policy partners in the human rights and mental health sectors.

There is a growing interest in the role of community and lived experience in mental health policy, and a stated desire to do things differently going forward. It is for NSUN to capitalise on this, and to lead the way in terms of articulating what rights-based mental health policies and practice, centring lived experience and communities, might look like.

Other Covid-19 related activities in March 2020 include keeping our website and social media up to date with useful information, guidance and specialist analysis for our members (a general update, official and VCSE information, mental health information, information for user-led groups, information on mutual aid, guidance on how to stay connected digitally, and analysis of the human rights implications.)

We also started working with Flexible Films on #NSUNCovidLife, a series of blogs and short, 3 min 'talking to camera' pieces from our members, to our members. We wanted to go beyond the mainstream guidance which doesn't speak to many of our members, and let our members speak about what matters to them - how they are experiencing this crisis, or how they are reaching out to others.

Hosted Projects

What is a hosted project?

Hosted projects are supported by NSUN, but carry out their work or activities under their own name. The arrangement will depend on the organisation, but sometimes NSUN provides administrative support or banking, or we can offer mentoring. NSUN used to be hosted by Together for Mental Wellbeing before it became independent. It can be a really good way to get a project or network off the ground, minimise financial risks and share learning.

Real Insight

Real Insight is a group of inspirational people with lived experience from secure settings and multiple disadvantages. Their work transforms services by creating a shift in culture. They achieve this by collaborating with service providers, involving staff, carers and peers through their innovative methods.

After four years of being hosted by NSUN, Real Insight are now independently managing their own day-to-day business activity, and have secured independent funding. NSUN is still providing some mentoring, and will continue to work closely with Real Insight.

"We have been able to successfully manage this due to the non-judgemental commitment from our host organisation NSUN. As a user-led organisation itself, NSUN empathise and use their own experiences and learning to positively support without prejudices despite the challenges we all face daily. These arrangements demonstrate the

benefits of peer-to-peer support at all levels. From our experience, we believe that newly set up user-led projects should always get the opportunity to get support from already established user-led organisations like NSUN." Nash Momori, Director of Real Insight

North East together

North East together (NEt) is the regional network for people with lived experience of mental health conditions living in the North East of England.

Since their launch at a conference in April 2009 that was attended by over 150 of the region's service users, carers and workers in the mental health field, they have carried out a variety of initiatives, usually led by our members letting them know what their priorities should be.

In the last few years, they have developed strong relationships with the statutory sector, and in particular with Public Health England and The Northern Clinical Network. They have worked closely with these and other partners on various pieces of work at a regional level including engaging with local service users and carers about plans for smoke free hospitals across the Region's two NHS Mental Health Trusts. From 2017 to 2020, they worked on 'A Weight off Your Mind', a regional plan to support people with mental health conditions and/or a learning disability in secondary services to lose/ manage their weight.

Their involvement in 'A Weight off Your Mind' included holding eleven focus groups across the region over the period of three years looking at how best to support people with mental

health conditions to lose weight. They consulted on what service users and carers thought of the first draft of the regional plan, designed case studies of people who used services and wanted to lose weight, and then looked at what the barriers to this were. Finally, their Secretary presented this work at three conferences to develop, launch and implement the plan.

In 2019/20, they also worked alongside The Northern Clinical Network to hold four focus groups across the region to ask people with lived experience of mental health conditions what good crisis care would look like. The original plan once the focus groups were completed was to present their findings at the region's Crisis Care Concordats to influence better ways of working. However, that phase of the work is currently on hold as a result of the Covid-19 pandemic and lockdown.

NEt is currently taking some time to work out how best to engage with their membership and the wider service user and carer communities across the region whilst lockdown continues and are in the process of applying for grants to support this work.

Reigniting the Space

Reigniting the Space is a project funded by the Lankelly Chase Foundation which aimed to map the current work mental health service users and survivors from racialised groups are involved in around the country. A Steering Group led this work and regional researchers were recruited to map two specific regions, the East Midlands and London.

Income 2019 – 2020				Expenditure 2019 – 2020			
	Unrestricted funds	Restricted funds	Total £		Unrestricted funds	Restricted funds	Total £
Grants & Donations	84,257	112,648	196,905	Staff and Project Costs	77,966	99,963	177,929
Contracts & Consultancy	39,177	0	39,177	General Running Costs	36,796	15,384	52,180
TOTAL	123,434	112,648	236,082	TOTAL	114,762	115,347	230,109

Financial Review

Income for the year ended 31st March 2020 totalled £236,082 (2019: £229,662) and increased by £6,420 from the previous year due to higher levels of one-off Contracts and Consultancy income. Grant income and donations fell in the year with donation income having been unusually high in the year to 31st March 2019 following the receipt of a large restricted donation in that year.

NSUN's principal source of funds during 2019-20 was income from grants from trusts and totals £190,258 (£2019: 196,440) and comprises 81% of income (2019: 86%).

Expenditure totalled £230,109 (2019: £258,635) for the year ended 31st March 2020, a reduction of £28,527 when compared with the previous year. Staff costs were reduced by £14,837 following the redundancy of two posts in the 2018/19 year and costs associated with the Reigniting the Space project which came to an end in 2019/20 were £14,711 lower. Other project costs which comprise mainly consultancy costs were also

slightly lower, as were general running costs where a reduction in finance support costs was seen. Fundraising costs totalling £8,434 were incurred during the year to the 31st March 2020 to support the team to apply for new sources of grant income.

Fundraising

A key aim for the financial year ended 31st March 2020 was to secure core funding to enable NSUN to plan and support user-led projects and respond to unplanned opportunities and initiatives.

The Trustees are delighted to report that new core grant funding was successfully secured in the year from The Esmée Fairbairn Foundation and the Tudor Trust totalling £258,000 starting from 2019/20 for a 3 year period and we are incredibly grateful for their support. We are also grateful for the ongoing support from Trust for London, The Local Mind Grants Fund, Lankelly Chase and Disability Rights UK (DHSC) for grant income to support various projects during the year.

Prior Year Adjustment

In preparation of these accounts it was noted that there were a number of errors in the results and position reported for the financial year ended 31st March 2019. The Trustees believe these errors to be material and as such have restated the SoFA and Balance Sheet as described in the full accounts. The adjustment made to the SoFA and Balance Sheet relate to:

- 1) The over statement of a dilapidation provision and related debtor surrounding a lease previously held by NSUN. A lower level of liability was agreed in February 2019 and the net impact of the adjustment to reduce the liability by £5,285.
- 2) The recognition of two restricted funds which had previously been omitted relating to the Survivor Researcher Network and Keeping Control project. A total transfer between unrestricted and restricted funds of £13,126.
- 3) The recognition of Gift Aid receivable totalling £2,500.

Income 2018-19 (restated)

	Unrestricted funds	Restricted funds	Total £
Grants & Donations	23,984	186,890	210,874
Contracts & Consultancy	18,788	0	18,788
TOTAL	42,772	186,890	229,662

Expenditure 2018-19 (restated)

	Unrestricted funds	Restricted funds	Total £
Staff and Project Costs	23,042	185,282	208,324
General Running Costs	20,984	29,327	50,311
TOTAL	44,026	214,609	258,635

4) The correction to bank balance in relation to unrecorded income.

Despite the need to restate the results at the 31st March 2019, this represented an administrative error and all restricted funds were spent in line with the restrictions placed upon them. Improvements to our financial systems to prevent future errors have now been implemented.

Total funds, reserves policy and going concern

Total funds at 31st March 2020 were £33,754 (2019: £27,781) and comprised restricted funds of £23,009 (2019: £25,707) and unrestricted funds of £10,745 (2019: £2,074). Restricted funds comprise core funding from Tudor Trust, funding from Esmee Fairbairn for communications support in 2020/21, funding towards the Keeping Control project and funds held to support work of North East together. The unrestricted funds

balance comprises income from contracts and consultancy as well as donations from individuals.

The Trustees review the charity's reserves policy annually and aim to hold 3 months of core costs in unrestricted reserves to cover the cash flow risk and statutory redundancy payments in the event of an unexpected need to close. We anticipate that core costs for 3 months total £44,000 and the Trustees have revised the reserves target accordingly. At the 31st March 2020 unrestricted reserves were 24% of this target. Trustees aim to set aside further unrestricted funds over the coming year but anticipate that it may take several years before reserves are maintained at this level.

The Covid-19 crisis has not impacted NSUN's ability to deliver activities and NSUN has been able to access short-term Covid-19 emergency funding to deliver several projects to support members with the impact

"From our experience, we believe that newly set up user-led projects should always get the opportunity to get support from already established user-led organisations like NSUN."

Nash Momori, Director of Real Insight

of Covid-19 in 2020/21. A Covid-19 Business Continuity Plan is also in place. NSUN has secured grant funding to cover all of its activities over the next 12 months and as such the accounts are prepared on a going concern basis. ●

The above information has been extracted from the full financial statements and is not intended to give a full overview of the financial performance or position of the charity. The financial statements from which the information has been taken have been Independently Examined and an unqualified report was given. The full Financial Statements, Trustees' report and Independent Examiners report can be obtained from info@nsun.org.uk or downloaded from the Charity Commission.

"My experience of NSUN is of a friendly, close-knit network of individuals and groups who care passionately about the rights, dignity and welfare of anyone experiencing mental distress. It's a place where I feel at home with my peers."

Zoe Kirby, General Manager of NSUN

The National Survivor User Network (NSUN) is an independent user-led network, bringing individuals and groups together to communicate, support each other, share experiences and have a voice. Crucially NSUN is a membership network led by people with the lived experience of distress or diagnosed mental health issues. It is a growing network with the strength to challenge inequality and improve lives. ●

OUR VISION

Our vision is for the lives of people who experience mental distress, discrimination and disadvantage to be better.

OUR MISSION

Our mission is to create a diverse, inclusive and influential user-led network with the strength to challenge inequality and improve lives.

OUR AIMS

- To create and strengthen links between individuals and groups.
- To support and promote user-led groups and initiatives.
- To influence and inform policy and decision makers.

OUR VALUES

- **Solidarity** – our network recognises commonality of interests and experiences, and facilitates mutual support.
- **Equality** – we believe all members should have equality of status, rights or opportunities.
- **Integrity** – we strive to express the views and experiences of our members in an unbiased and unfiltered way.
- **Diversity** – we understand, recognise and value difference - our different backgrounds, experiences, ethnicities, beliefs and abilities.

We are here to make sure the voice of experience is heard.

The NSUN Board of Trustees submits its statutory Report and Accounts for the year ended 31 March 2020.

The Trustee's Report and Financial Statements have been prepared in accordance with the Companies Act 2006, the Charities Act 2016 and comply with UK Generally Accepted Accounting Practice (GAAP). They also comply with the Accounting and Reporting by Charities: Statement of Recommended Practice (SORP) in accordance with the Financial Reporting Standard, also known as the Charities (FRS 102) SORP.

Exemptions from disclosure:

This annual report does not omit or withhold any reference or administrative details.

Public benefit statement

In reviewing our aims, objectives and activities, the trustees have taken into account the Charity Commission's general guidance on public benefit. The trustees ensure that the activities undertaken are always in line with the charitable aims and objectives as set out in NSUN's governing document. This annual report does not include exemptions from disclosure. ●

NSUN would like to thank our supporters who have recognised that we are doing a valuable job for our members and the wider community and that we are worth funding for the future

- **The Esmee Fairbairn Foundation**
- **Health and Wellbeing Alliance**
- **Lankelly Chase**
- **Mind**
- **Trust for London**
- **Tudor Trust**

Together we are stronger



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2020**