The science of effective advocacy for children and families

Prepared for Congenital Hyperinsulinism International, The Hague, Sept 2023

Professor Sir Al Aynsley-Green Kt

Background:

Being a clinical scientist successfully generating research grants from prestigious organisations including the UK Medical Research Council meant that I was fully aware of the need for rigour in preparing the application for funding – a clear statement of the hypothesis to be tested, detailed description and justification of the proposed methods, clarity in budget and assessment of dissemination and likely impact. Research applications that failed to comply with this rigour were unlikely to be considered.

Against this when in the Department of Health in Government in England as the first National Clinical Director for Children I sat with Ministers with large numbers of people from a range of organisations who came to see us to argue for their own pre-occupations and agendas to be noted and ideally, funded. I realised quickly that the many had not prepared themselves to argue their cause effectively – indeed some of them didn't really have clarity in what they wanted!

The Scientific Advocacy cascade

Accordingly, as the first Children's Commissioner for England, I road-tested a 'scientific advocacy cascade' to improve rigour in advocacy. The components of this are:

1. Understanding the cause being advocated for.
2. Having the facts to justify the cause.
3. Crafting the argument to be irrefutable.
4. Knowing who to target.
5. Brigading colleagues to speak with one voice.
6. Using the media.
7. Defining metrics for impact.
8. Follow through to assess efficacy.

The first project we tested was the plight of young people admitted inappropriately to adult mental health wards when suffering from mental ill health. The need for this was drawn to our attention by listening to the young people themselves.

Thus, we defined the cause – to stop the inappropriate admission of young people to these wards. We garnered the facts by working with the charity *Young Minds* to describe qualitatively the lived experiences of being so admitted alongside getting quantitative statistics from official sources. We crafted the argument into a formal report *'Pushed into the Shadows'.*

We informed the offices of relevant ministers and colleagues in the sector. We worked closely with the BBC in producing television and radio news slots on prime-time news programmes of the difficulties in young people's mental health. We published the report timed to coincide with a key parliamentary debate on mental health and sent a copy of the report to every parliamentarian the day before the debate.

Ministers acknowledged that there was an issue and gave a promise that within two years no young person would be admitted inappropriately by investing in new adolescent in-patient facilities.

Great, you might say! But what happened as a result? One year later we published our second report *'Out of the shadows'* documenting the ways in which local services were or were not taking action to prevent such admissions. It confirmed that many organisations had not taken seriously the mandate from government to improve services. Those who had not complied were named and shamed directly and in reports to government.

These events have been forgotten in the flurry of recent concerns over child and adolescent mental health, and we know that such admissions to adult wards are still taking place. So, the wheel must continue to turn if not be reinvented.

Other successful examples of the Scientific Advocacy Cascade include the steps taken to get parliamentary focus on the impact of alcohol during pregnancy, the plight of young unaccompanied asylum seekers facing deportation and in forcing a huge 'climb down' by the Secretary of State and ministers over their intention to remove the legal powers developed over 80 years from local authorities to protect the most vulnerable children in social care.

Understanding the cause to advocate for

Understanding what is being advocated for is fundamental to getting change in services, yet how poorly this is understood, with many initiatives being driven by the needs of professionals within their bunkers and silos and not after actually listening to the needs of patients and families.

A better way to design services is to use the construct of the **patient's journey**, its milestones, and considering the needs of the patient, the family, and the staff at each milestone.

Thus, in the case of CHI, the milestones can be identified thus:

1. Awareness that all may not be well in pregnancy eg a very large fetus; insatiable appetite in the mother
2. All is not well with the new-born infant showing seizures, feeding difficulties and irritability.
3. Diagnosis of hypoglycaemia usually by a blood sample from a heel prick.
4. On-going concern leading to more detailed investigations from larger blood samples.
5. Confirmation of on-going hypoglycaemia with inappropriate concurrent levels of insulin in the blood; further genetic analysis and radiological examination of the pancreas
6. Introduction of medical therapy
7. Surgery when medical therapy is ineffective or when a focal lesion is identified in the pancreas.
8. Post-operative stabilisation with or without concurrent medical therapy
9. Discharge to home with local immediate supervision
10. Progress through infancy and childhood with or without post-pancreatectomy diabetes mellitus; need for continuous glucose monitoring.
11. Management of developmental and cognitive challenges in schools.
12. Transition to adult services

Already CHI has identified that the needs of parents at the time of confirmation of the diagnosis is often non-compassionate by medical staff with little understanding let alone support for the grief that families will face when their eagerly anticipated baby is shown to have not only a problem, but a very serious problem with life-long implications for the child and its family.

The needs-based journey construct can be used as a template in designing

and delivering effective services and support for families and can also be used in describing the management plan to individual families.

It also reminds services to address the needs of staff in understanding and managing the illness, including their requirements for teaching and training.

Translating research into policy and practice

A further aspect of advocacy is translating findings from research into policy and practice. In the face of massive pressures from universities to gain 'Brownie points' for research productivity, researchers are driven to a vicious cycle of getting new grants and publishing results without time or reward in translating the findings of completed studies into policy and practice. But the translation into policy and practice has to be the benchmark for success, and this can be thought of in the context of the cascade.

An important way forward is for academic organisations to generate resources to pilot and develop projects that *they* want to take forward and are not dependent on the funder's pre-occupations.

Getting professionals aligned.

Getting successful changes in practice demands the engagement of professionals. In my experience, this can be incredibly difficult to do, resistance to change being due to the following as exemplified by real comments made to me:

- *Territorialism: 'I'm in the NHS, you're in social care and I think you're in education!' 'I'm a GP, you're a hospital consultant'; you're a school nurse, I'm a practice nurse'.*
- *Tribalism: 'I'm a physician, you're a surgeon'; 'you must be a secondary school teacher, I'm in primary school'.*
- *Traditionalism: 'We've always done it this way, why should we change?'*
- *Tunnel vision: 'Sorry Al, haven't time for this, I'm a world- famous specialist, 30 patients waiting in my clinic!'*
- *Timidity: 'And besides which, it's not my job!' Its for others to speak out'*
- *Terror: 'What if we get it wrong?'*
- *Treasury: 'We haven't got the money, so why bother?'*
- *Tiredness, exhaustion and cynicism: We've been here before, Al, nothing's going to change and thank goodness I'm retiring in 6*

months time!'

These illustrate the massive challenges in attempting to get change especially at a time of demoralisation and disaffection caused by austerity, the impact of Covid 19 and political uncertainty. Effective, dynamic, and inspirational leadership are essential to overcome the resistance to change – yet where is it? How can potential leaders be identified and be nurtured?

The armed services invest massively in developing leadership at all levels, but in my view, our public services and specially the children's sector have not done so with sufficient energy or clarity other than providing organisations to teach to deliver the political dogma of the day.

How do we develop a robust understanding of leadership? My own journey has been greatly influenced by the work of John Adair and Steven R Covey. But why isn't there a cross-sectorial initiative for potential leaders in health, social care, education, and youth justice to work and train together outwith the demand of government to implement policy?

Conclusions

CHI is embarked on an inspirational mission to improve the quality of care given to children and families experiencing the exceptionally difficult illness that is congenital hyperinsulinism.

Already the work has exposed serious issues in the 'journey' through the disease from first recognition that all is not well with the infant, identification of hypoglycaemia, steps to diagnosis and management leading to long-term on-going care. Major difficulties are then reported by families in being able to access medical, social, and educational support for the children as they grow up.

These children and their families need and deserve effective advocacy for these needs to be met, yet so often it is reported that agencies do not know of or understand these needs. In many instances it is not the fault of the agencies that they don't understand, it's because they haven't been told through effective advocacy!

CHI has an outstanding opportunity to grasp this science and be a leader in the support sector for babies and families with a rare disease, and its processes and findings need to be disseminated.

References:

Aynsley-Green A: Translating research into political advocacy to improve infant and child health

https://pubmed.ncbi.nlm.nih.gov/25260960/

Aynsley-Green A: The British Betrayal of Childhood.
https://www.taylorfrancis.com/books/mono/10.4324/9781315098937/british-betrayal-childhood-al-aynsley-green

Author:

Professor Sir Al Aynsley-Green Kt.

Former first National Clinical Director for Children; first Children's Commissioner for England; past President, British Medical Association.

November 2023