

Commentary on “Wales and Autism: The Impact of Philanthropy Matched with Ambition”

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Commentary on “Wales and Autism: The Impact of Philanthropy Matched with Ambition”

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3 **Commentary on “Wales and Autism: The Impact of Philanthropy Matched by**
4 **Ambition”**

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8 **Abstract**

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10 **Purpose:** This paper is a commentary that aims to address themes arising from the article
11 by Morgan entitled *“Wales and Autism: The Impact of Philanthropy Matched by Ambition”*.
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15 **Approach:** This opinion piece considers the broader impact of stakeholder engagement in
16 the field of Autism, including how the dissemination of evidence-based support could be
17 made more accessible for autistic people, their families and carers, and philanthropists.
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21 **Findings:** This paper highlights the link between stakeholder engagement and meaningful
22 change in policy and practice in the field of autism. It highlights the need for philanthropists
23 to invest in evidence-based support but highlights the difficulty in identifying and accessing
24 such support. This piece supports the use of evidence and gap maps to increase the
25 accessibility of autism research and evidence.
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29 **Originality:** While stakeholder engagement is encouragingly rising in this field, most of the
30 evidence is held in academic journals, which are behind paywalls and, therefore,
31 inaccessible to many autistic people, their families, carers, and associated professionals.
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33 Displaying evidence using evidence and gap maps provides an accessible way for autistic
34 people and those who support them to identify possible avenues of support quickly and
35 allows philanthropists to direct research funding to areas of high priority.
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39 **Keywords:** Autism, Evidence, Stakeholder Engagement, EGMs, Evidence and Gap Maps,
40 Evidence-Based Support
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44 **Paper type:** Viewpoint
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Introduction

Philanthropic contributions have significantly shaped the landscape of Autism support. The significant impact that philanthropic efforts have made in driving scientific research and shaping comprehensive care for autistic individuals should be highlighted much more in academic journals. Notable philanthropic initiatives such as Autism Speaks, the Autism Science Foundation, and Autism Cymru have funded ground-breaking research, explored early intervention strategies and spear-headed advocacy efforts to destigmatise autism, leading to greater public understanding and acceptance.

Moreover, philanthropy has facilitated the establishment of specialised educational and therapeutic programmes tailored to the unique needs of autistic people. These programmes have provided opportunities for skill development, social interaction, and improved quality of life, empowering autistic people to reach their full potential (Laugeson *et al.*, 2012). Philanthropic contributions have also underpinned the creation of community-based organisations that offer vital support networks for families, advocating for their rights and helping them navigate the complexities of autism-related care and services.

Philanthropy and Evidence

Morgan (2023; this issue) demonstrate the multi-faceted role philanthropy had in the development of Autism Cymru, demonstrating how it not only advanced Autism research but fostered a sense of belonging and empowerment within the autism community providing a compelling argument for society to continue championing these endeavours. For this to happen and to ensure such efforts result in a meaningful impact in the lives of autistic people, we need to continue in our efforts to close the gap between research and practice, such that evidence-based supports are transparent to autistic people and those that support them. Philanthropic organisations and donors often rely on evidence and research to guide funding decisions. By investing in programmes and initiatives grounded in research and evidence, philanthropists ensure their contributions are more likely to have a meaningful impact. They frequently fund research projects aimed at understanding the causes of

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3 Autism, developing effective interventions, and improving the quality of life for autistic people
4 (Pellicano *et al.*, 2013). But what happens when this research is behind a paywall? How do
5 we ensure that the public, including philanthropists and philanthropic organisations have a
6 thorough understanding of what makes something 'evidence-based'? A review of UK Autism
7 policy documents highlighted that recommendations for specific evidence-based supports for
8 autistic people are difficult to identify, and where specific evidence-based supports are
9 recommended, such as in the National Institute for Health and Care Excellence (NICE)
10 guidance, this is technical, and perhaps inaccessible for those without an understanding of
11 research methodology and complex data analysis (Storey *et al.*, 2023). The lack of
12 signposting towards evidence-based supports for Autism is understandable, given the
13 complexity of Autism. The heterogeneity of Autism can result in difficulty tailoring research
14 findings to meet the diverse needs of autistic individuals, and the need for personalised,
15 individualised support often strengthens the case that bridging the gap between research
16 findings and practical implementation will require continuous effort (Happé *et al.*, 2006).

33 **Research-to-Practice Gap**

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35 A fundamental challenge in the research-to-practice gap is the delay in translating
36 research findings into interventions and services that can meaningfully impact the lives of
37 autistic people and those supporting them (Kim, 2016), and this challenge begins at the point
38 of dissemination. Publishing autism research findings is an integral part of building an
39 evidence base for a particular intervention or guideline, and doing this in academic journals
40 is a standard practice that allows for robust peer review and dissemination of scientific
41 knowledge (Odom *et al.*, 2010). However, academic journals are not always readily
42 accessible to the general population. Many journals require a paid subscription or access
43 through a university or institutional library, creating a financial barrier for those seeking
44 access to current and past research. They are often written in complex and technical
45 language that may be difficult for individuals without background knowledge of the field.
46 While there is a growing movement towards open access requirements which will give
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3 philanthropists and autistic people and those that support them the ability to read research
4 articles, determining whether something has an evidence base is a time-consuming and
5 often cumbersome task that requires collaboration between practitioners, policymakers,
6 autistic people, and those that support them (Dingfelder and Mandell, 2011). This process is
7 further complicated by the fact that 'evidence' is not synonymous with peer-reviewed
8 publications in academic journals. It is widely understood that academic journals tend to
9 favour the publication of positive or significant results, resulting in publication bias (Ioannidis,
10 2005). Focusing solely on academic journals results in the rich data in reports, unpublished
11 dissertations, and theses being overlooked.

22 **Evidence and Gap Maps**

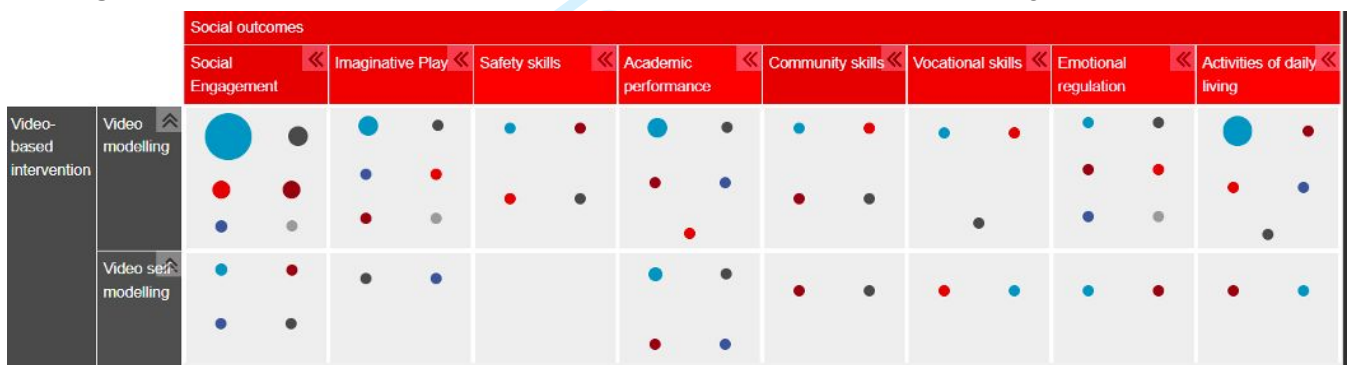
23
24 Evidence and Gap Maps (EGMs) systematically collect and organise information
25 from various sources, including academic journals, reports, dissertations, and theses, to
26 visually represent the current evidence on a specific topic. EGMs go beyond summarising
27 existing evidence by highlighting areas (or supports) where there is a clear evidence base,
28 or where evidence is lacking and research gaps/uncertainties exist. Therefore, researchers,
29 policymakers, and philanthropists can use EGMs to identify priorities for future research
30 (Haddaway *et al.*, 2015), and autistic people and those who support them can identify
31 evidence-based supports that could positively impact their lives.

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33 EGMs are comprised of evidence bubbles or icons representing individual studies or
34 pieces of evidence. Each bubble may contain key information about a study, including the
35 title, authors, publication year, and a summary of findings. Colour-coding is often used to
36 indicate the quality or strength of evidence. For example, studies with a high risk of bias may
37 be represented in red, while studies with a low risk of bias may be represented in green,
38 presenting a visual summary of the available evidence, making it easier for decision-makers
39 (including philanthropists) to understand the current state of knowledge on a particular topic
40 (Snilstveit *et al.*, 2013).

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An ongoing systematic review and meta-analysis into video-based interventions for promoting positive social behaviour in children with autism developed an EGM to display the available evidence in this field (Keenan *et al.*, 2021). A sample of the EGM is displayed in Figure 1, and immediately, the lack of available evidence in using video self-modelling for supporting the development of safety skills can immediately be seen. The map uses evidence bubbles to display the saturation of evidence in specific areas, for example, the large blue bubble in the field under 'social engagement' and besides 'video modelling' demonstrates that there are many single-case experimental design studies in this area. On the live map, various filters can be applied such that policymakers, philanthropists, autistic people, and those who support them can see the available evidence across specific domains.

Figure 1: Video-based interventions for autistic children: An evidence and gap map.



Conclusion

Morgan (2023; this issue) demonstrates in "*Wales and Autism: The Impact of Philanthropy Matched by Ambition*" philanthropy's powerful impact in eliciting meaningful change for autistic people and those who support them. Researchers in the field can take an active role in facilitating the efforts of philanthropists by being cognisant of the accessibility of their evidence. In particular, researchers focusing on evidence synthesis (systematic reviews, meta-analyses, and other scoping/rapid reviews) should consider using EGMs alongside their reviews. EGMs are a valuable tool for informing decision-making in an accessible way and ensuring valuable resources are allocated where needed most.

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