



“Informed Solutions for Better Outcomes”

Summary Report

November 2022

Pilot duration April 2021 to September 2022

A Collaborative Partnership

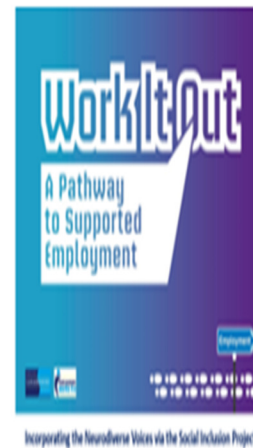
Collaboratively Authored by Dr. Thom Kirkwood, Bill Colley, Ramon Hutchingson.

The Pilot Partnership



SC050788

Neurodiverse
Voices



CLC
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ARCH, COAST, SAIL, SLC, SLHSCP, Logos provided by ARCH. Other provided directly

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Foreword



Val De Souza

It was an immense honour to be asked to write this foreword, and to be able to introduce a wonderful collaboration that will make a real everyday difference to people and their families and carers, supporting practitioners and professionals alike.

As Chief Officer of the South Lanarkshire Health and Social Care Partnership (2016 -2021), I was approached by both Ramon Hutchingson, the Co-ordinator of ARCH (the Autism Resources Coordination Hub), and Thom Kirkwood formerly from Autism Network Scotland with a proposal to pilot a programme called the Development and Wellbeing Assessment tool (DAWBA) – a tool originally developed in the 1990’s with considerable evidence-based research and proven practical application. The DAWBA complemented the “My Autism Profile,” an accessible, early self-assessment and profiling tool developed at the ARCH, which was co-productively developed. The expertise of Bill Colley, Chair of the Scottish Attention-Deficit / Hyperactivity Disorder (ADHD) Coalition charity, in using the DAWBA added much valuable insight. Working together brought a real meeting of minds with one crucial ambition – to make sure autistic people and others with neurodevelopmental conditions owned, guided and self-directed their screening, assessment, support, and care activity.

The Health and Social Care partnership did not hesitate to support this pilot, the DAWBA was clearly a well-researched and accredited programme. It is important to note that DAWBA sits comfortably alongside existing NHS diagnostic processes and clinical tools. It is heartening to see the model so widely endorsed and already being successfully used by bodies such as NHS England and Wales, The British Association of Social Workers, The British Psychological Society, and the National Institute for Mental Health in the U.S. as well as currently being used in Denmark as a diagnostic approach.

The strengths of this approach include

- A timely, cost-effective indicative assessment
- Help to reduce screening waiting times faced by many children and young people in relation to suspected neurodevelopmental conditions including autism, ADHD, and other psychological and clinical conditions.
- With both the backlog associated with the pandemic, and significant pressure on services the tool offers the chance to identify children and young people’s indicative presentation at an earlier stage, enabling crucial interventions to be mobilised in a timely, tailored and person-centred manner, whilst other formal diagnostic and assessment processes were still pending.
- Getting the right services and supports, at the right time, delivered by the right people is an additional benefit the tool offers, aligning seamlessly with current national and local policy and strategic aspirations including amongst many others; ‘Getting It Right for Every Child,’ ‘Fulfilling the Promise’ and ‘Inclusion as Prevention’

The DAWBA embodies the spirit of co-production, ensuring that the child or young person is firmly at the very centre of all considerations relating to their lives, and both they and their networks of support remain fully engaged and consulted in all decision-making processes using a robust rights-based approach.

We are now currently at the threshold of a post-COVID Scotland, where a recovery plan and fairer future for all is promised, particularly those in need of clinical or social care interventions and no better time for this DAWBA Pilot in Scotland.

You will read in the following report that the initial aspirations for the DAWBA have been met, and indeed exceeded. Many participants report that by being kept central to the entire process from beginning to end, the choices, flexibility and control they have exercised in relation to the supports offered to improve their lives, has been truly respected. This is warmly welcomed and a credit to those who had the vision and tenacity to believe in this project and generate such significant changes and outcomes for these communities.

When reading the following report, you may also make the following observation “uninformed solutions do not solve problems,” and the DAWBA offers us all; individuals, parent carers, volunteers, and professionals a real chance to make informed and genuinely co-created decisions together with the communities we serve.

Val de Souza
Chief Officer (Retired)
South Lanarkshire Health and Social Care Partnership

Executive Summary

1. The results of the pilot project support recommendations made by Woolgar et al in the 2014 NSPCC report that the SDQ/DAWBA could play a valuable role in addressing the currently unmet needs of non-clinical professionals at an earlier juncture when timely and informed decision-making and planning for children and young people (and their families) is required and could prove invaluable.
2. The SDQ/DAWBA could be deployed as a cost effective/high-impact measure to reduce the well-documented consequences of prolonged wait times and diagnostic bottlenecks which can delay interventions by non-clinical professionals and negatively impact on those users and carers affected by their decisions. A core strength of the SDQ/DAWBA is its capacity to generate highly accurate indicative profiles at/closer to the point of need when informed decision-making is paramount.
3. The SDQ/DAWBA as used in this pilot, could offer significant “invest-to-save” benefits with respect to ‘Getting It Right’ for children and young people to avert placement breakdown, declining mental health and poor long-term outcomes.
4. The pre-diagnostic properties of the SDQ/DAWBA could also support non-clinical professionals to gain greater insight into the severity, complexity and potential consequences of children and young people’s unmet support needs as well as potentially averting avoidable crises.
5. Considerable potential exists for the SDQ/DAWBA to be deployed at an epidemiological level to inform broader planning objectives across large population sets (e.g., local authority/health board).
6. The objectivity of the DAWBA could reduce potentially adversarial exchanges between users, carers, and other resource gatekeepers by re-focusing discussions on a less potentially biased manner and at a more asset-based level to the benefit of all concerned.
7. The project did not elicit any major unforeseen consequences or negative responses from participants their families or project partners.
8. Further research should be undertaken to determine with greater accuracy the impact of the SDQ/DAWBA on professionals working with young people, and the practical implications of a wider, non-clinical assessment approach of this type.
9. Access to the project and the benefits of participating were universally welcomed by parent/carers as well as the majority of supporting practitioners and professionals.
10. The rated assessments delivered a higher degree of ‘equitable empowerment’ for participating individuals, their parent carers, informal networks of support, teaching

staff, allied health professionals, mental health practitioners' and social care staff leading to shared, timely and informed interventions.

Overview

The pilot team undertook this exploratory baseline pilot project as a 'coming together of minds' after collaborative exchanges considering the potential non-clinical application of the Strengths and Difficulties Questionnaire (SDQ) and the Development and Well Being Assessment (DAWBA) - both tried and tested assessment tools. This evolved into consideration of the DAWBA **as a triage tool applied in practice, a proposition mooted in an NSPCC paper by Woolgar (et al) in 2014 titled; - 'What Works in Preventing and Threatening Poor Mental Health in Looked After Children'** as well as reflecting on other reviews, reports, and action plans.

These early discussions raised some **'What if?'** questions; --

➤ What if

- ❖ There was an accurate, timely, cost effective, supportive assessment process available that could provide a detailed, indicative wellbeing profile of various neurodevelopmental conditions and psychiatric disorders.
- ❖ This could help select and direct the allocation of resources for further assessment, earlier identification, and/or timely, tailored support services by encouraging joined up approaches.
- ❖ A pilot study could identify if the SDQ/DAWBA might improve collaborative practice to the benefit of assessed individuals, their families, support practitioners, and professionals?
- ❖ A baseline study could identify challenges and enabling factors required for improved partnership working.
- ❖ Potential revenue, resources and quality of life savings might ensue from a modest investment in such an approach?
- ❖ The combined clinical & non-clinical application of this approach could bring formal and informal support networks together, reducing adversarial exchanges?

Conclusions

The strengths we identified in using the SDQ/DAWBA:

- The SDQ/DAWBA instrument can provide timely, cost-effective, and unbiased indicative assessments
- Implementation is likely to lead to significant reductions in initial screening processes, and consequential waiting times faced by many children and young people., a factor identified in several reports including The Audit Commission for Scotland in 2018.
- With both the backlog associated with the pandemic, and significant pressure on services the tools offer the chance to identify children and young people's indicative presentation at an earlier stage, enabling crucial interventions to be mobilised in a

timely, tailored and person--centred manner, whilst other formal diagnostic and assessment processes remain pending.

- Getting the right services and supports, at the right time, delivered by the right people aligning seamlessly with current national and local policy and strategic aspirations including amongst many others; 'Getting It Right for Every Child,'(GIRFEC), 'Fulfilling the Promise' and 'Inclusion as Prevention'
- The approach did not conflict with, or contradict other assessment approaches, whether clinical or otherwise such as, ADOS, ADI-R, DIMENSIONS, ESSENCE or SCERTS.
- In contrast with current widely acknowledged delays, assessment took an average 92 days from consent to identified actionable outcomes, interventions, or diagnosis
- 74.87% of suggestions were identified as actionable thus far
- Final reports informed decisions regarding identified needs
- Self-directed partnerships enhancing practice between formal and informal networks
- There were significant Improvements in:
 - Service targeting
 - Tailored Interventions
 - More timely Interventions
 - Enhanced self-directed partnership actions
 - Enhanced/Improved multi-disciplinary & parallel working

Suggestions/recommendations:

1. Improvements could be made to the user-experience (UX) of the on-line assessments through:
 - i. greater use of visual supports
 - ii. enhanced section on environment and sensory issues
 - iii. improved accessibility for 'Apple' technology
 - iv. creation of an optional 'app' format
2. The inclusion of a supplementary questionnaire for social care professionals would broaden the scope of the wellbeing assessments to facilitate enhance multi-professional dialogue.
3. Additional support may be required in completing questionnaires, due to literacy and or language barriers.
4. Development of this pilot or equivalent model incorporating a piece of multi-disciplinary learning which might promote the identified benefits of timely consent to share of information. This could also lead to a shared starting point where practitioners could agree and share the same assessment report, in practice with service users and their networks of support.
5. A formal academic randomised control study could explore in greater depth the benefits of an enhanced, holistic, and truly inclusive wellbeing overview assessment,

with timely, targeted services, tailored interventions and the benefits for individuals and their families.

6. A financial modelling exercise could be undertaken to consider the potential cost-saving benefits such an approach could offer in terms of social return on such an investment.
7. Further research into the efficacy of the SDQ/DAWBA in assessing the needs of non-English speaking children and young people.

The data (a very brief overview):

- 11 Project Partners
- 8 Nominating partners for participants.
- 51 Participants
- 37 Completions and report issues.
- 21 Feedback and evaluations
- 172 Questionnaires; comprising a mix of individuals, parent carer and professionals
- 117 Self-directed report and advocacy responses shared.
- 329 Indicative Wellbeing Concerns
- 207 Suggestion for further Considerations
- 155 (74.87%) Actions identified in partnership between families and professionals

“As parents it was particularly good to see something that captured a more holistic overview of our daughters’ challenges. It confirmed we needed support, further assessment, and explanations. Without this our daughter could well have ended up leaving school with no supports.”

“A report like this would enable us to make better more informed decisions”

Childrens Panel Members

“This could be 1000 times better than what we have at present”

Team Leader, Youth Justice, Social Work

“As both a parent and lead practitioner, I found this pilot to be very partnership orientated, individualising and supportive for and to all”

The pilot team would like to thank our partners, our participants, and their families as their partner professionals. Thank you.

This unfunded project was designed and delivered with no conflicts of interest.

Further enquiries or copy of full report please email Dr. Thom Kirkwood = thom@aiseecollaborative.co.uk

