“Informed Solutions for Better Outcomes”

Pilot Project Report

January 2023

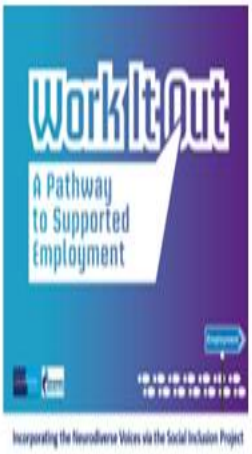
Pilot duration April 2021 to September 2022

A Collaborative Partnership

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

The Pilot Partnership

Neurodiverse Voices



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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.

The Main Report

i) Introduction
ii) Why what we do matters?
iii) The Assessment Tool
iv) The Advocating Response
v) Analysis
    a) Critical
    b) Statistical
vi) Case Studies
vii) Reflective Learning
viii) Conclusions
ix) Suggestions/Recommendations
x) Thank you and Acknowledgements

Introduction

The coming together of minds from advocacy and education with a shared joint concern on the need to 'get better' at assessing 'needs at an earlier stage.'

Like all positive things they often start by an informal conversation, this Innovatively Individualising Triage Pilot Baseline Assessment is no different. Four years ago, Thom Kirkwood formerly from Autism Network Scotland was introduced to the Development and Well Being Assessment Tool, DAWBA, by Bill Colley, Educational Neurodevelopmental Specialist, who at that time had been using the tools for more than three years. The outcome of this triggered a big **What if?** And several other related questions we posed:

What if there was an **accurate, cost effective and person-centred assessment tool** available which could provide a **comprehensive indicative profile as well as highlight** various neurodevelopmental and/or psychological conditions. A timely, non-biased way to select and direct the allocation of targeted services with tailored interventions, and suggest the need for further assessment where required, enabling a '**whole team'** approach?

- **What if**
  - i) there was an **accurate, cost effective, supportive assessment process** available that could provide a **comprehensive indicative wellbeing profile** of various neurodevelopmental conditions and psychiatric disorders.
  - ii) this could help select and direct the allocation of resources for further assessment, earlier identification, and timely, tailored support services by encouraging '**whole team'** approaches Granulated further for this pilot to two questions?

- Would a pilot study identify whether the SDQ/DAWBA could potentially offer improved collaborative practice to the benefit of assessed individuals, their families, support practitioners, and professionals?

- Could a baseline study identify the challenges as well as enabling factors required for improving collaborative partnership working, and what potential benefits this could result in a social return of investment?

It has been used **as an assessment tool** in a number of **UK** national surveys as well as other countries internationally, the totality of which highlighted **its accuracy**. One of these studies suggested it was time for an 'evidence test.' Thom concluded that an ideal subject to assess the **practical** application of the DAWBA **as a triage tool** was a close relative.

By DAWBA as Triage we mean, - Can a DAWBA overview report be useful to and for non-clinical professionals, families, to enable service targeting and informed decision making.

"If this assessment was used earlier in a relative's assessment, would it have provided both reassurance and more beneficial information more informed decision making and could it for others going forward?"

The SDQ/DAWBA, is an internationally tried and tested **diagnostic tool** created by Professor Robert Goodman, Child and Adolescent Psychiatrist, Kings College London in the mid-nineties. The tool has more than **4500** academic and peer reviewed citations within a searchable database of **DAWBA publication**. [1]

The SDQ/DAWBA questionnaires were duly completed and to Thom's surprise the **rated** report outlined his relative's presentation and **indicative support needs** with remarkable accuracy, as well as posing several further considerations **including** family reassurance. Thom recalled a previous discussion he had with a group of health clinicians in his former role as Director, The Patients Association. This related to another assessment approach; the **Balint Method**.[2] At the time this was and remains as a comprehensive approach to mental health needs. When considered alongside the DAWBA, something of a ***flashbulb moment*** occurred and the journey which eventually led to the present pilot was set in motion. This was the realisation that both approaches represented accurate, comprehensive, **and timely** overviews of mental wellbeing needs.

In support of this insight, a significant Case Review into the death of a young person caused by suicide within one local authority area concluded that [3]

'Strategic planning of mental wellbeing and mental health services, informed by data on need and outcomes, should ensure that mental health expertise and resources are more evenly spread across the support continuum.'

and with one consideration within the areas to consider

'Greater involvement of local mental health experts, working in operational services and schools, in planning and strategy. Shared design of mental health services across primary and secondary health, social care and schools aiming to strengthen the whole continuum of services from prevention through to targeted expert help.'

Question: Could we build on previous learning?

This baseline exploration assessment was initiated to build on previous higher-level research looking into the efficacy of the DAWBA and take this a step further forward to look at the tool's **practical application and potential to improve early identification**.

This was a question posed in 2014 by NSPCC, Rees Centre, University of Oxford - **'What Works in Preventing Poor Mental Health in Looked After Children'** [4]

Could there be a potential benefit and impact for those not in the looked after system if assessed using the SDQ/DAWBA?

The 'usefulness' of assessment instruments in research depends on their ability to detect change in individuals over time; their usefulness as clinical screening tools depends on whether they are capable of predicting mental health service need (when used by non-clinicians) or, for clinicians, whether they can help to select and direct the allocation of resources or further diagnostic assessments. Ease of use Preventing and treating poor mental health in looked after children is also an important consideration. Taking this range of uses into account, key findings that emerged from the review included:

'Use of the Strengths and Difficulties Questionnaire (SDQ) with looked after children has been shown to provide a good estimate of the prevalence of mental health conditions, allowing the identification of children with psychiatric diagnoses based on the Development and Well-Being Assessment (DAWBA).'

'Caregivers' and teachers' responses on the SDQ have proven to be more useful than self-reports and its use as a screening tool during routine health assessments for looked after children has been shown to increase the detection rate of socio-emotional difficulties.'

'The SDQ, Child Behaviour Checklist (CBCL), Children's Global Assessment Scale (CGAS) and DAWBA can be scored and assessed to determine children's clinical needs. The SDQ, CBCL and CGAS may be more useful as broad measures of well-being than for assessing specific conditions.'

'The DAWBA's use of diverse types of questions and added focus on patterns, duration and impact of symptoms may explain why it is most effectively used by clinicians, especially with complex cases where clinical judgements are needed.'

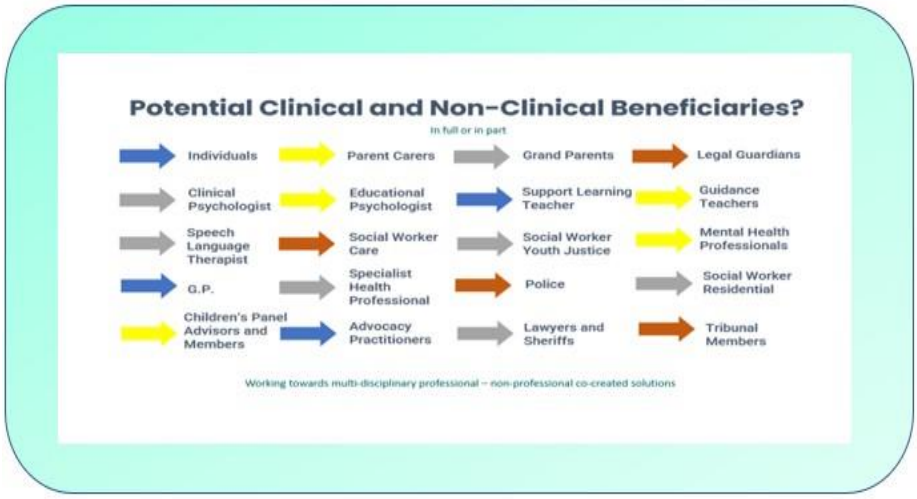
'The reliability of assessments depends on who is completing the instrument; in what context; and the skills of the person interpreting them…'

***Note** – In Scotland we now refer to 'Looked After Children as 'Care Experienced.'*

Question: Who could be potential beneficiaries?

Adopting a pause to enable reflection, this brought to the fore a number of questions – associated to unmet needs from challenges faced by individuals, parents, and carers, as well as clinical and non-clinical professionals.

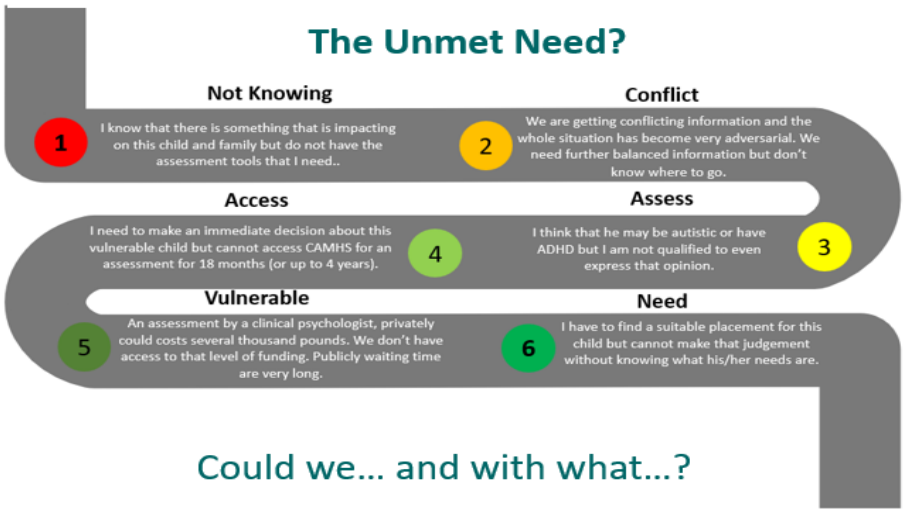
This Infographic illustrates our initial view that the answer to this could be wide and varied.



Question: What are the potential barriers reported most frequently, from parents, carers, and professionals alike?

- undue clinical diagnostic waiting times,
- undue waiting times for in-school assessments
- undue waiting times for social care assessments and interventions,
- "The right hand doesn't talk to left," practitioners in different settings delaying or failing to share their assessments with individuals, families and across agencies
- bureaucracy and requests for assistance taking too long,
- Individual and family views and experiences being excluded, dismissed, or even ignored
- there are not enough knowledgeable people within the workforce,
- why do we not listen to each other?
- we need a shared language!

Such barriers **'an unmet need'** *see image opposite* are very real and prompt the need for urgent changes in practice. They are also supported by a growing body of evidence that there are systemic weaknesses in terms of the cohesion between agencies and lack of collaborative assessment and planning between agencies principally education and child and



adolescent mental health. These impact provision for children with additional support needs on a daily basis and outlined in reports including **All our Children and All Their Potential** [5] **Not Included, Not Engaged, Not Involved** [6]

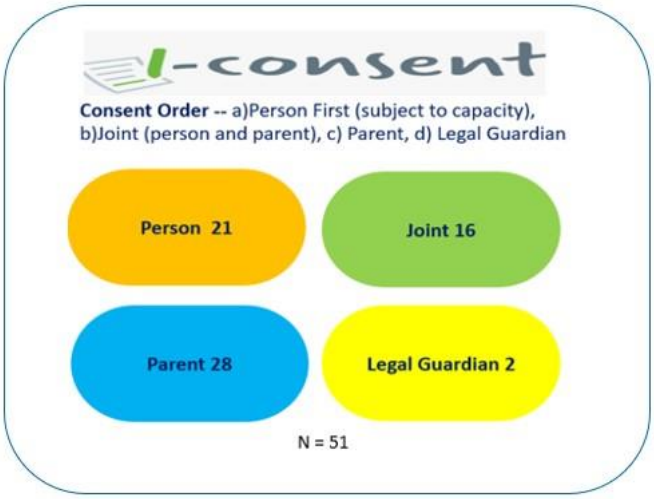
What are Scotland's overarching intentions? Are there improvements that can advance and support those intentions?

The intention, here in Scotland is clear. The direction of policy and legislation is towards early intervention, inclusion, and equality. However, these remain aspirational principles. Unfortunately, they still falter when it comes to joined up delivery.

"Could a multi-disciplinary, non-clinical early identification approach be of benefit utilising the SDQ/DAWBA?" We believed so, hence our discussions in developing this pilot.

One would expect differing perspectives in the answers, but we thought there had to be better ways of operating cohesively toward improved delivery in practice associated to **GIRFEC,(Getting it Right for Every Child)**, [7] and supporting the implementation of the **National Practice Models** [8] whilst at its core supporting Scotland's continued implementation in practice of **UNCRC**,[9] and **incorporation into Scots Law.** [10]

We therefore recognise - The United Nations Conventions on the Rights of the Child, ratified in the UK in 1991, formerly at least in theory, into practice consideration 1992, and decided to align the pilot with these principles; person-centred, human rights based, and consent driven.



We know the development and well-being assessment tool has been successfully used in a number of national surveys including key public bodies, for example: -

The report of a survey carried out in 1999 by Social Survey Division of the Office National Statistics on behalf of the Department for Health, the Scottish Health Executive and the National Assembly for Wales – '**The mental health of children and adolescent in Great Britain**'[11] and by **NHS Digital Mental Health of Children and Young People in England,** 2017,[12] and **Mental Health of Children and Young People in England, Wave Two Follow Up 2021** [13]

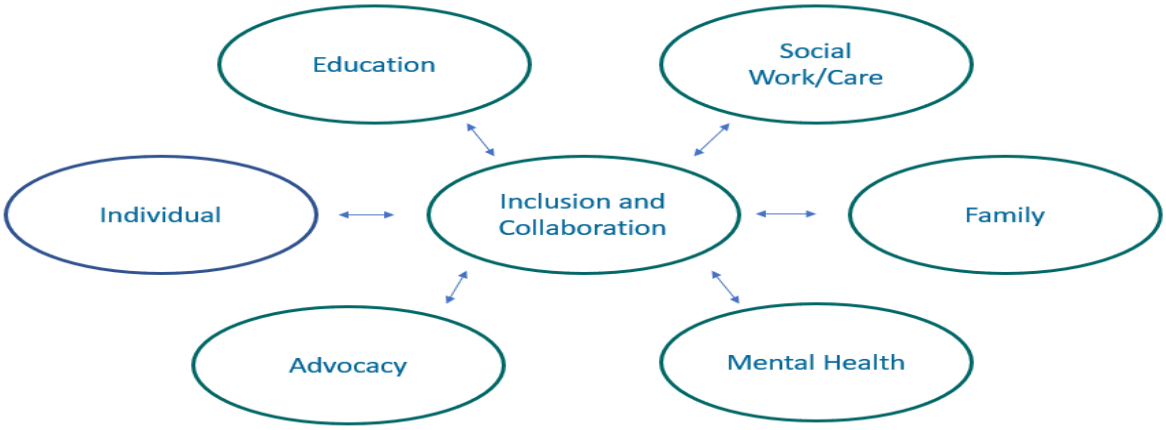
The pilot team also believed that as well as improving practice, inclusive integrated thinking could offer potential benefits for taxpayers' pounds and potential societal return on investment expounded in the **Microsegmentation Report March 2018**. [14]

Evolving into broader strategic considerations, we realised a series of additional, yet significantly relevant considerations especially with connectivity and cohesion in practice aligned within policy. *An opportunity to identify investment proficiency!*

In parallel, ARCH, South Lanarkshire and The Renfrewshire Autism and Neurodiversity Project, Renfrewshire HSCP joined the discussions as potential pathway partners, with Renfrewshire seeking participation for adults only. Given the DAWBA's academic citations predominantly related to children and young people, it was recognised there was insufficient academia to support such a consideration.

Further discussions including clinical oversight, ethics and processes, strategic potential as well as practical implementation continued within a professional context across Scotland. Inclusive of reflection on **Why what we do matters?**

For this pilot project we have **- the coming together of minds** from individuals, families, education, social work/care, mental health, and advocacy, with the shared joint concern on the need to 'get better' at assessing 'needs at an earlier stage.'



After considerable deliberation we arrived at the conclusion that there was justification to establish a study to explore the use of the potential of practically applying the SDQ/DAWBA as an early identification profiling triage tool within a Scottish context guided by our fundamental what if's?

Why what we do matters!

Despite Scottish Government ASN funding increase overall, even pre-pandemic, certain departmental or specialist funding has not kept pace with the increase in demand.

It could be reasonably argued more so, when account is taken of comorbidity rates and the prevalence figures of children and young people in both the care and youth justice systems.

Prevalence All Increasing (For example but not limited to)	More than 4/5 people with ASC/D have ADHD traits
ADHD 1 in 20	Between 1 in 2 and 1 in 4 children with ADHD have ASC
Autism 1 in 57	1 in 3 people with ADHD have Development Coordination Disorder/Dyspraxia traits
Development Coordination Disorder 2%-6% (e)	1 in 3 people with Development Language Disorder have Development Coordination Disorder
Developmental Language Delay 7.6% (e)	Around 1 in 2 people with Tourette's syndrome have ADHD traits
Dyslexia 1 in 10	More than 1 in 5 people with Dyslexia have ADHD traits
Tourette's 1% (e)	Developmental Language Disorder and Dyslexia often overlap
NDC – unidentified within Social Care System 44% (e)	
NDC – unidentified within Youth Justice System 45% (e)	

This information has been drawn from various reports, reviews for example ADHD UK, Autism Resource Centre Cambridge, Dyslexia UK, Ican.org.uk, BMJ, Sage Publications

It seems there is scope to use the SDQ/DAWBA as a triage tool in supporting those at the front-line and articulated by the following anecdotes:

"This family is struggling, it is evident it is not poor parenting, I need this child assessed"

Social Worker

"I can't help this child until I know what the issues are?"

Teacher

"I know there is something wrong with my boy but what?"

Parent

"I know this girl needs support, but I can't access an assessment to give me my starting point?"

Teacher

"I have to find a suitable placement for this child but cannot make a judgement without knowing what their needs are."

Social Worker

"My daughter will have left school without the help she needs to meet her needs due to very long wait times"

Parent

"I need access to an assessment that will help me support this young person here and now."

Social Worker

"As dad I am along with my daughter's teachers fed up trying blindly to meet a need when we don't know what it is!"

Dad

The need for change has been articulated via increasing demand, lived experiences and data drawn from research. In addition to qualitative sources the pilot team sought to build and expand upon previous work, including reviews, reports, and academia. We agreed that a baseline study of a **timely**, **comprehensive indicative wellbeing profile could support the principles of inclusion as prevention and address findings such as those below:**

In an investigation by **Scottish Public Services Ombudsman** [15] into the Moray Council's decision make around one family affected by autism and other complex issues, they **found**

'Under complaint (a) we found that the records evidence that the attitude of social work was at times judgemental and based on pejorative private opinions' and 'Under complaint (a) we found that there were numerous and significant failings in relation to gathering and taking into account relevant information when making decisions regarding the children's care and education'

A **Significant Case Review** [16] of one young autistic person within one local authority areas concluded that

'... concerns were not always shared effectively with all key partners, as they were being considered in isolation'

In respect of **Initial Case Reviews** (ICR's) and **Significant Case Reviews** (SCR's) a recent **Cultural, Artistic and Scientific Knowledge for Prevention, Access, and Retrieval** (CASPAR) [17] briefing stated,

'Issues around addressing the mental health and wellbeing concerns of older children mean young people aren't being referred to Child and Adolescent Mental Health Services (CAHMS) or children's social care appropriately.'

In April 2019, pre covid the Scotsman [18] reported a data analysis presented by the **Scottish Childrens Services Coalition**, a leading children's campaign group which highlighted

'...a "dramatic increase" in the number of Scottish school pupils identified with a range in neurodevelopmental conditions.... autism up by 101%, child mental health problems up by 252% emotional and behavioural challenges up by 87%, those with communication challenges up by 293%...'

And from The Scottish Government Commissioned **All our Children All Their Potential** [5]

*"**30.9%** of children and young people in schools in Scotland have an additional support need"*

and

"That additional support for learning is not visible or equally valued within Scotland's education system...."

A System which

"**... devalues and demoralises children and young people** who learn and achieve in other ways..."

With the DAWBA's proven history as child and adolescent mental health assessment tool, if utilised, due its comprehensive wellbeing overview may provide an opportunity to reflect and build on access to and accessibility of accurate assessment information useful and beneficial for other non-clinical practitioners, across education and social work and more.

It was concluded by project partners that it was worthwhile undertaking this Innovatively Individualising Triage Pilot, as an observational baseline assessment project. Our purpose would be to identify the benefits of the SDQ/DAWBA applied as a non-clinical profiling tool and focus upon:

- identifier of individual strengths and difficulties
- identifier of underlying indicators

- provide an enhanced holistic person-centred overview benefit to (a) individual (b) parents (c) practitioner (d) professional
- associated timeline prompting more timeous for targeted and tailored interventions
- associated cost, time, and timeline savings
- value of SDQ/DAWBA Report as supporting information for subsequent clinical diagnosis

with an overarching consideration re potential impact on early identification, for earlier targeting of service provision and individualised tailored interventions.

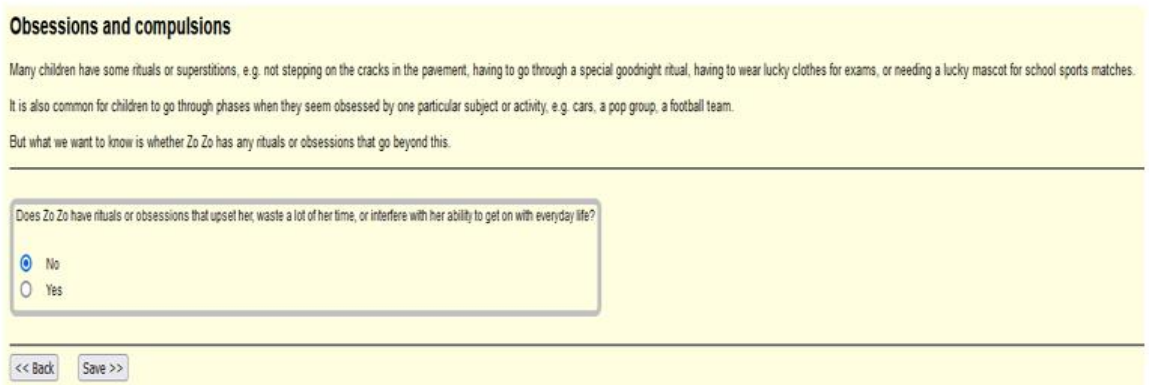
The Assessment Tool (Information supplied by DAWBA Team)

The DAWBA is a package of interviews, questionnaires and rating techniques designed to generate ICD-10 and DSM-IV or DSM-5 psychiatric diagnoses on 2–65-year-olds. The DAWBA covers the common emotional, behavioural and hyperactivity disorders, without neglecting less but sometimes more severe disorders. You can consult a list of diagnoses covered.

Information is collected from up to three sources:

- An interview with the parents of 2–17-year-olds.
- An interview with 12–25-year-olds themselves.
- A questionnaire completed by teachers or another practitioner of 2–17-year-olds.

The DAWBA interviews can be administered either by humans or by computers. For the ever-increasing proportion of young people and parents who are at home with computers, the computer-administered interviews [19] have the advantage of cutting out the cost of employing an interviewer. Below is a screenshot selection of the online provision.



In addition, some respondents find it easier to be honest with a machine than a person. There is also a convenience factor since a growing number of respondents can complete the 'online' DAWBA from home or work. But there are also many circumstances where having

an interviewer is an advantage. It is quick to train DAWBA interviewers and previous clinical experience is not essential, see Interviewers' Instructions [20]

The interviews and questionnaires involve a mixture of closed questions such as "Does he ever worry?" and open-ended questions such as "Please describe in your own words what it is that he worries about?" With the computer-administered interviews, the respondent types the open-ended answers into the text boxes. With the interviewer-administered

interviews, it is the interviewer who transcribes the answers. Interviewers can also add comments to the transcript, e.g., about a respondent's difficulty understanding questions, or about a respondent's reluctance to speak about specific topics.

To increase acceptability and reduce costs, the interviews and questionnaires have deliberately been kept as short as possible. As a rough guide to length, the parent interview takes around 50 minutes to administer to a community sample. The corresponding youth interview takes around 30 minutes to administer to a community sample. The teacher questionnaire takes around 10-15 minutes.

The length of interviews is further reduced by *skip rules* that allow entire sections to be omitted when screening questions indicate that the child is extremely unlikely to have the diagnoses covered by those sections.

Information from the different informants is drawn together by a computer program that also predicts the diagnosis or diagnoses, generating six probability bands, ranging from a probability of less than 0.1% of having the relevant diagnosis to a probability of over 70% of having the relevant diagnosis. The computer-generated predictions may be enough for some research studies, but for clinical use and some research studies, the computer predictions are not the finishing point - they are simply a convenient starting point for experienced clinical raters who decide whether to accept or overturn the computer diagnoses (or lack of diagnoses) in the light of their review of all the data, including transcripts.

The DAWBA combines the simplicity of respondent-based measures with the oversight of a counsellor or psychologist. Getting respondents to complete the interview online can reduce costs by 80% or more. If interviewers are needed, then using non-clinical rather than clinical interviewers reduce costs. Skilled clinical investigators are expensive and scarce - the DAWBA uses them very economically. For example, the 1999 British nationwide survey employed around three hundred non-clinical interviewers to assess over 10,000 children - but only required two clinical raters back at base.

The initial validation study of the DAWBA suggested it had considerable potential as an epidemiological measure and promise as a clinic assessment Goodman et. al., 2000. [21] A decade of subsequent experience has confirmed this. The DAWBA has been used in all the British nationwide surveys of child and adolescent mental health, Meltzer, Gatward, Goodman, & Ford, 2003. [22] These surveys, and similar surveys in many other countries, have generated reasonable prevalence rates, and shown the expected pattern of association between disorders and independent risk factors - thereby providing further

evidence for the validity of the DAWBA. The DAWBA has also taken off as a clinical assessment in a wide range of contexts and countries.

Over and above the routine rating process adopted by the DAWBA, as part of this pilot we have a dual overview of the algorithmic generated report. Firstly, by a high experienced, trained rater, followed by further overview not just to the generated report, but to the rater's overview considerations and suggestions. Consultant Clinical Psychologist do this second overview.

In ensuring a robust and objective rating process, a two-tiered screening arrangement was put in place. The first rating was undertaken by a DAWBA trained and accredited rater, followed by a second tier of clinical oversight by a Consultant Clinical Psychologist.

Later reference is made to identified conditions within the final generated wellbeing profile, and both 'probable diagnosis' and 'indicative diagnoses' referenced.

Advocacy Response

The pilot team are consciously aware of the challenges autistic individuals, their families, and those with other neurodevelopmental conditions often have in accessing timely, targeted, and tailored interventions. Equally the demands and pressures practitioners and professionals have in their endeavours to meet those needs via targeted service provisions.

We are all appreciative through our experiences irrespective of our roles, that some of the interfacing conversations in addressing these challenges can be complex, uncomfortable and in far too many situations become unnecessarily adversarial.

Advocacy can play a significant contributory role in alleviating aspects of those challenges, whilst at the same supporting and enabling individuals, their families, practitioner, and professionals to achieve solutions for going forward in positive collaborative ways.

Unfortunately access to advocacy for autistic people and those with other neurodevelopmental conditions and their families is currently a postcode lottery of commissioned or grant funded services, often part of statutory advocacy provisions.

There is already a national strategic context to meeting the challenges of access to advocacy, often controlled by eligibility criteria, which has the dual impact of service limitation.

Individuals' families and communities/ groups of people may need a range of diverse types of advocacies, and it is vital that advocacy provision is available appropriate to need, delivered by the right people at the right time.

Advocacy need has been recognised across a range of reports and plans, for example, **The Promise**, [23] ***The Accountability Gap***, [24] ***ASL Action Plan***, [25] **The Autism and Advocacy Exploration Report**, [26], **The Microsegmentation Report**, [14] the latter two both part of the Scottish Strategy for Autism. Most recently the **Autism and Advocacy Policy Action Paper** Jan 2022 [27], which is due to be followed up by further submission to policy leads by the Autism Advocacy Network.

Given the significant and clearly known gaps in advocacy provision, the pilot team in shaping the pilot determined along with the DAWBA Report that we would provide an advocacy component by means of 'Advocacy Response' intended as a helpful guide in suggesting further steps.

When it comes to autism and other neurodevelopmental conditions, one realises advocating is often and more often than not, more than a single issue and it is about the person, the team including family, the processing and system, with outcome beyond more than an output.

The focus of considerations and suggestions from a DAWBA report, have within the advocacy response have taken account of the overall common interest holistic advocacy approach via a positive collaborative partnership where all adopt a co-productive participatory engagement resource in practice.

The objective is a ‘gentle suggestive nudge’ for Inclusion as Prevention by Inclusive and Together.

In adhering to a rights-based approach, it was suggested to twenty-five participants and their families that they may have had a statutory access to Independent Advocacy provision due to mental health or additional support for learning legislation. Unfortunately, twenty-three were unsuccessful, two were successful, one receiving advocacy, the other family support. Does this in itself highlight an advocacy supply problem or narrow eligibility criteria?

Analysis

As well as the raw data we are able to pull on from the DAWBA reports, Participant Overviews, we have also included the evaluation questionnaire which follows. We have incorporated responses from those into our critical analysis, statistical analysis, case studies and reflective learning.

Evaluation Questionnaire

We have one more request from you. Would you, your supporters be so kind as to complete this evaluation questionnaire below.

This has been an exciting and interesting baseline exploratory project. This project team and our nominating partners would like to thank you for participating. We thank your supporters, family, practioners and professionals who have help you.

It is important to re-emphasise this project was unfunded and the pilot team committed to this without remuneration.

Evaluation Questions

Please tick your nominating partner agency

Nominating Partner	Cross One
AISee	
ARCH – Autism Community Resource Hub -- ARCH	
CLC Consultancy	
COAST – Champions of Autism Spectrum Together	
RANP – Renfrewshire Autism and Neurodiversity Project	
SAIL – Supporting Autism in Lanarkshire	
Silent National Partner	
Work it Out	
Other Please Name	

Did the project information leaflet and consent form inform you sufficiently with where applicable
further granulated information from your nominating partner agency.

	Yes	No
Did this collectively explain your rights?	Yes	No
Did you request any reasonable adjustments made?	Yes	No

Please indicate

How did you find the questionnaire?

Please indicate.

What would you suggest could be done to make it easier and or more relevant?

Please Indicate.

Was there anything you thought obviously missing?

Please indicate.

Did you find the report useful? Yes No

Did you think it was accurate re you? Yes No

Please indicate.

Do you propose to use the report? Yes No

Do you intend to, or have you shared the report? Yes No

Who do you intend to share the report with?

Please Indicate – (e.g., Teacher, Spec Teacher, Ed.Psych. Clinical Psych. GP. SALT. OT.) You can indicate as many people or organisations as you wish.

How do you propose, if at all, to use the report?

Please indicate.

Do you think it will add value in determining any outcome with the people or services you share the report with?

Yes No

Please indicate.

Will it contribute to a reduction in adversarial conversations with people about your care, diagnosis or in place support?

Please indicate.

Has it help to attain targeted service to support you and or tailored supports for you? Please cross all that are applicable or appropriate.

Target / Tailored Provision	**Cross all Applicable**
Comprehensive School Observation	
Identify General Learning Profile/Plan	
Identify Strengths and Weaknesses	
Potential Islands of Competence	
Promote Self Esteem / Reinforcement of success	
Promote Positive Interactions	
Enhanced Transitions	
Social Skills Assessment	
Support Self Awareness	
Masked Disorder or Masking weaknesses	
Adult Screening for Additional or Differential Assessment re DX	
Screening for Additional or Differential Assessment re DX	
Social Competence Functions /Language SPLD/Comms Passport	
Cognitive Functioning /Profiling/ Match to Attainment	
Sensory Assessment and Profile	
School Adjustments re Anxiety / Demand Led Challenges	
Academic Adaptations re Curriculum	
Explore Open Text Answers	
Comprehensive Development Disorder Factors	
Emotional and Development Factors	
Executive Function Deficits	
Determine Risks (Self Harm/Substance/Sexual)	
Eating Difficulties	
CBT potential Benefits re Anxiety/OCD	
Increase Social Inclusion (Support) and QOL v Attainment Goals	
AHP Assessments SLT % or OT	
Social/Friendship Inclusion and Development	
Clarification of Age/Stage expectations/supports	
Psychological Interventions re PTSD	
Family supports	
School Staff Supports	
Individual feeling safe (inclusive of social fears)	
Recent bereavements noted and support options explored	
Workplace Adjustments	
Voice being Heard / need for trusted adult	
Post School Planning	
Reasonable Adjustment in Employment	
Improved Individualised Employment Placement	
Disabled Student Support Application	
Other	

Additional Comments

As a professional supporter did you find the report informative? Yes No

Did the report information assist you to target service better with tailored supports?

Please expand.

Did the report enable you and or such service to tailor support more beneficially for the individual?

Please expand.

Do you think such a report is beneficial in early more holistic wellbeing identification?

Please expand.

Was the soft advocacy response, where issued, useful as a guide? Yes No

Please expand

It is worth noting that all the way through this pilot process, participants, families, and partner practitioners and or professionals were asked to inform us which policy/practice areas they could identify potential benefits. All evaluation and feedback points, many repetitive have been incorporated into the report and or the selection of case studies.

Critical Analysis

Given that the principal aim of the project was to evaluate the efficacy of the DAWBA as a **comprehensive indicative wellbeing profiling** triage instrument to inform thinking and planning for professionals working with children and young people, this section of the report will focus not only the DAWBA per se, but on the practical considerations involved in making it available to that client group (including for example, social workers, teachers, residential care managers, youth justice workers, members of the Children's Panel, etc.) or as appropriate to the team around the child.

The process

Beneficial to begin with by illustrating the participants overall journey within this pilot project, see illustration opposite.

When a new referral was registered with the project and completed the compliance process, the case was passed by the Project Coordinator to the DAWBA Rater with the following information:

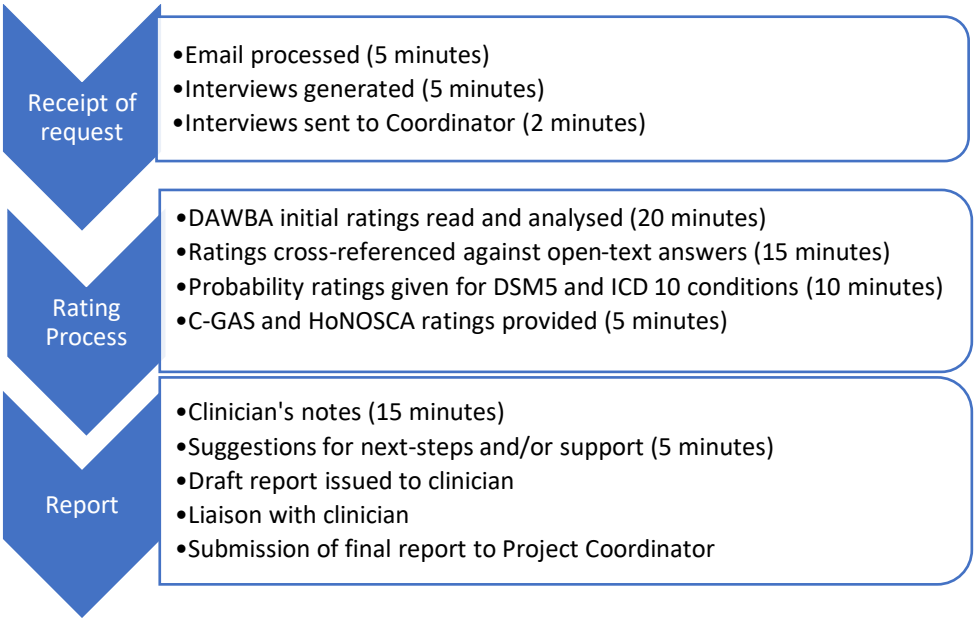
1. Age of child/young person (CYP)
2. Gender of CYP
3. Number of structured interviews required
4. Type of interviewee

No further information was provided.

The project Coordinator then assigned an identification code (e.g., J13M) to allow both Rater and Coordinator to liaise over the interview process without compromising data held exclusively by the coordinator.

Interviews slots were then generated by the Rater and the on-line links sent by email to the coordinator who then distributed these to the client.

On completion of the interviews, the Coordinator would alert the Rater who would then complete a draft rating profile before sending this as an inclusive part of the full DAWBA report to the Clinical Supervisor, who would then either endorse the report or suggest additional information, changes in style or tone, or make any other recommendation before the report was forwarded by the Project Coordinator to the client, along with a soft advocacy response.



The rating processes

The specificity and sensitivity of the DAWBA algorithm have been established through the normal scientific process of peer reviewed research. The rating process, whereby these initial findings are then used to guide the development of a full profile requires considerable experience in the field of diagnostic assessment across a range of developmental and mental health conditions and the rater must have the confidence to 'challenge' an indicative finding or suggest that others are added-in as considerations.

Thus, in terms of the study group:

- Initial suggestions of OCD were sometimes dismissed/over-ruled if the behaviours were comforting rather than intrusive.
- Indications of Bipolar disorder were frequently questioned or over-ruled due to the age/stage of the client, and if there was no evidence of true 'mania' or if 'hyperactivity' might provide an alternative explanation
- Where ASD emerged as a strong possibility, anxiety and phobias were considered in this context rather than as discreet disorders.
- ASD was occasionally suggested as a possibility where not otherwise indicated if there was sufficient evidence to suggest that self-report was itself influenced by this condition.
- Where 'trauma' was suggested in the client history, PTSD might not be rated if the full diagnostic criteria were not evident in client responses.
- CD and ODD were treated with caution in clients with ASD or ADHD where behaviours were context-specific (e.g., prompted by anxiety).

In all cases, and as would be expected in an exercise of this nature, the main recommendations or suggestions were for further assessment using specialised clinical services, or for further information gathering.

Clinical oversight

The pilot did not seek to employ the DAWBA to generate diagnoses or initiate treatment, rather this was an opportunity to see how a generalised profile might be of benefit to non-clinical professionals. However, to maintain a degree of rigour in the assessment process all generated indicative profiles were reviewed by a clinical psychologist to ensure that they met a minimum standard for accuracy by those who would be potentially using them.

This also allowed potential actions to be attuned to the requirements of local available clinical and social services.

There were no significant disagreements between the Rater and the Clinical Supervisor, but the latter was able to add further insight on occasions and to suggest changes of style and tone to avoid potential difficulties in consulting with existing clinical professionals and ensure the DAWBA was regarded as offering added value and insight rather than challenge pre-diagnosed conditions.

Risk Management

Prior to the establishment of the project, consultations took place with experienced DAWBA raters to determine what, if any, risks might arise.

The principal concern that emerged from those discussions was the issue of 'safeguarding' and how the project team should manage any disclosures that could indicate immediate risk to a CYP.

It was agreed that the Rater and Clinical Supervisor would alert the Project Coordinator at the earliest opportunity should such a situation arise, and that the coordinator would them contact the referring agency to determine what action should be taken. One of the Pilot partners retains a 'Reserved Function' via a statutory agency in this regard. Agreement was reached that any potential Child or Public protection concerns would be involve his guidance.

Four such cases arose and were actioned by the project coordinator via pilot partner with 'Reserved Function' within 2-3 hours of issue being flagged up. Three out of the four had already been seen by CAMHS with each having a determination. One, more severe, had an imminent appointment with local CAHMS Crisis Team.

"I have already had a positive response to this report from the CAMHS" Crisis Team."

Instances of severity we hope would always be met by the fundamental principles within Scotland's Suicide Prevention Action Plan 2022-2025, 'Creating Hope Together' [28] by the practice inclusion of

"……. Time, Space, Compassion…"

In the event where, any person may be at risk of significant harm, national guidance for child and adult protection would be followed. If this came across as imminent, then emergency services would be informed.

The second set of risks concerns possible 'false positive' and 'false negative' results, i.e., that a condition might be suggested by the DAWBA that was not actually present or one missed that should have been included in the final profile.

Given that the project was not aiming to provide definitive diagnoses, any subsequent demonstration of inaccuracy would fall into the field of diagnostic uncertainty' rather than being classified as an error. In many cases, DAWBA probabilities were matched against DSM5 criteria to ensure diagnostic compliance and only time will tell how prospectively accurate the DAWBA was at identifying the correct range of psychiatric and psychological conditions provided in the probability profile.

A third identified risk is the potential for parents/carers to misinterpret an indicative suggestion to imply that a definitive diagnosis had been given. This, despite considerable efforts to clarify the purpose the indicative profile to all participants, this possibility has been shown to have occurred and one requiring further consideration.

In cases where abuse or neglect may be under consideration as a factor in a CYP's presentation, the DAWBA made no attempt to contribute towards this differential formulation but instead offered additive value in identifying potential independent factors which could also be part of that process.

Furthermore, accuracy in assessment hinges on the quality of information disclosed and this varied in this pilot as it does in the clinical situation.

Finally, the project was not aimed at providing or initiating treatment but guiding support and thus a recommendation based on one indicated condition would not be likely to cause harm if a different one was present.

Recommendations/Suggestions

The dilemma facing the Rater and Clinical Supervisor was how best to convey the findings of the DAWBA rating in terms of the language and nomenclature employed.

At an early stage it was decided to re-phrase 'recommendations' to 'suggestions' to reduce the risk of offence to those who might feel that the project was attempting to undermine or challenge existing services.

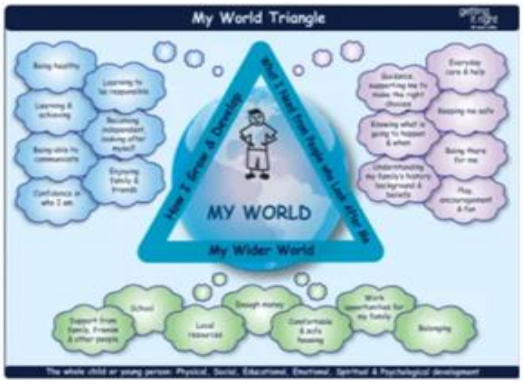
As indicated above, the most common suggestion was for further assessment and in particular the value that could be added to an understanding of a CYP's needs by a comprehensive school observation. It is worth emphasising:

> *"Those involved in the DAWBA ratings noted the potential added-value to the assessment process of good quality school observations exploring pupil mood, behaviour, and social interactions in both structured and unstructured environments to demonstrate functioning in more than one domain."*

> *"DAWBA raters frequently suggested that an understanding of pupil needs would be enhanced by input from allied health professionals and in particular speech and language and occupational therapists."*

In terms of practice, this approach fits nicely and complimentary to and along with the DAWBA in terms of undertaking welling being assessments, it is supportive under the GIRFEC framework [7] alongside assessments for reasonable adjustments and additional support for learning needs. The DAWBA assessment is available within the NHS provisions and can be used within existing assessment pathways.

[7]



[7]

In other cases, it was suggested that allied health professionals might undertake assessments to determine with more precision, the current function of a CYP in terms of speech, language, and communication, or where issues had been indicated with respect to sensory processing.

In a small number of cases, the level and/or complexity of need suggested that families/carers may benefit from additional support, but this could not be explored in any depth without reference to the locale, and the availability and capacity of existing services. However, the suggestion itself could encourage those involved in supporting the CYP to investigate specialist maintained, third sector, or other options, and was thus considered to be worth including in the final report.

Critical Analysis Summary

1. The administration process worked effectively and efficiently but could be improved in the following ways:
    a. DAWBA IDs should be used in preference to Coordinator-generated identification codes
    b. The update tools in the DAWBA system, including the 'To Do' list could be used more effectively by the Rater to assess on-going progress
    c. There is a yet un-demonstrated concern that information disclosed in the participant's overview might be excluded from the DAWBA interview because the participant may wrongly conclude that the Rater already has access to it.

2. Whilst there was confidence that the ratings were valid, the robustness of the results could be improved, by:
    a. Providing on-line support prior to the issuing of interviews to explain the process prior to completion
    b. Providing support to help participants understand the value of more in-depth open-text answers, particularly with reference to the.
        i. Frequency of behaviours
        ii. Intensity of behaviours
        iii. Impact of behaviours
    c. Increasing the number of interviews
    d. School participation

3. Participants might benefit from having direct access to the Rater or Clinical Supervisor to understand what the final DAWBA report means.
4. Some minor glitches in the DAWBA itself require attention, and specifically the gender pronouns used in the report which can mis-identify individuals.

Statistical Analysis

From the pilot partnership, the key geographical partners via the ARCH - Autism Resource Coordination Hub - are strategically South Lanarkshire Health and Social Care Partnership, and South Lanarkshire Council with the following third sector or inhouse partners, namely; Action for Children, Champions of Autism Spectrum Together, Support Autism in Lanarkshire, Work it Out -Including --Social Inclusion Project, Youth Justice South Lanarkshire.

The other three partners were: Bill Colley CLC, Caledonian Learning and Care – Educational Specialist & Neurodevelopmental Specialist. Thom Kirkwood, AISee Consultancy – Advocating Inclusion Specialist, Change Agent, and Trainer and Renfrewshire Autism and Neurodiversity Project.

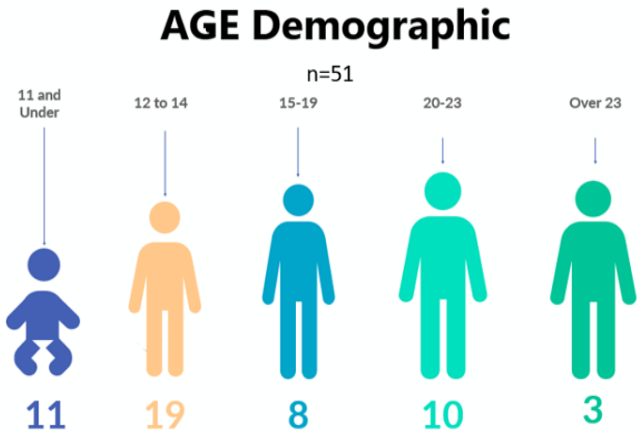
Neurodiversity Voice was integrally inclusive throughout, inclusive of neurodiverse individuals, parents, carers, and professionals.

Most pilot partners were Nominating Partners, where they could nominate individuals for participation. Others provided both nominations and expertise, others just expertise.

In this infographic, one can see the number of nominees per nomination partner.

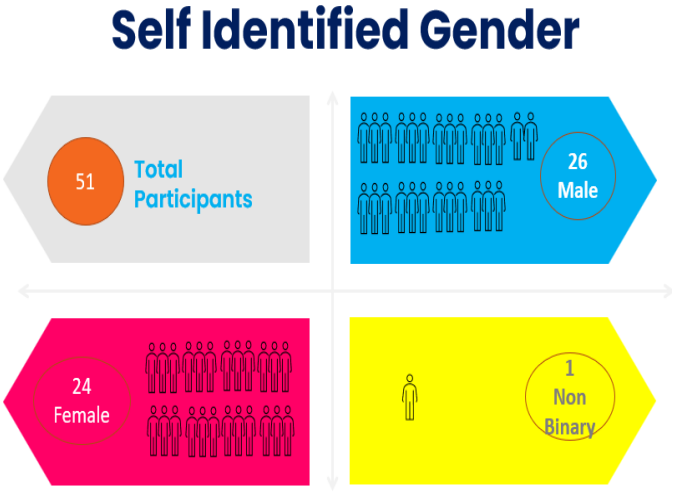
Nominating Partner	Number of Nominated Participants
Action for Children via ARCH	2
AISee	4
ARCH	33
COAST via ARCH	2
RANP	3
SAIL via ARCH	2
Work it Out/SIP via ARCH	4
YJSW via ARCH	1

n = 51

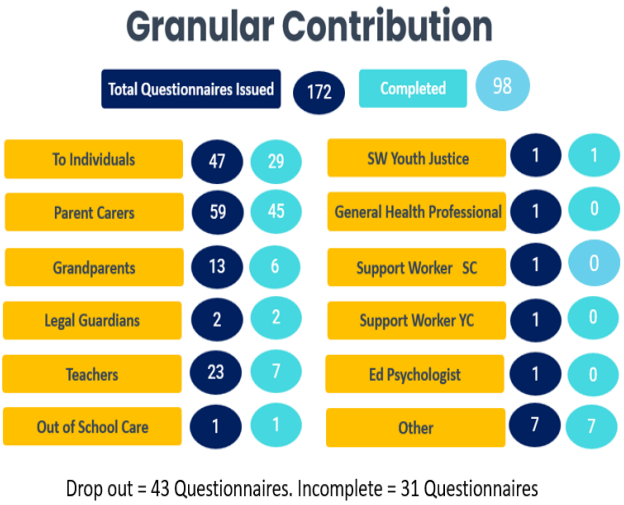


The target age range for nominated participants was set between 7 years old to 23 years old, with a caveat, we would accept a small number below 7 and over twenty-three, with the aim of objective learning and comparisons if and where possible.

The neighbouring infographic provides the breakdown the age demographics of the project participants. In line with modern thinking and of course consent. We enabled self-identified gender, as per the infographic below. We did not provide a choice option. We simply allowed an open box within the Participant Overview document, to enable the individual/parent carers or legal guardians to enter their own choice.

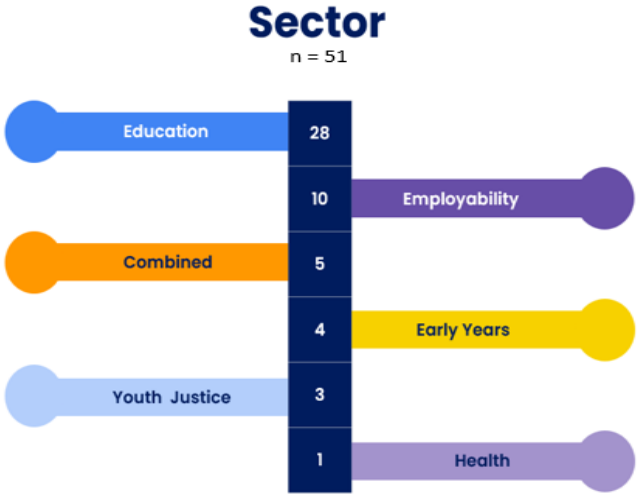


The participants came from across Central Scotland, the majority from West Central, with the remainder from East Central. The infographic below provides a further breakdown.



There were six provision/services sectors from which the participants came. Unsurprisingly the majority came as expected from within education. What was surprising, was the small number of combined sector participants e.g., education/social work, education/social care, employability/social care. There were only five identified as combined.

The nomination process was via a nominating partner, as this built in an additional safeguard for participants and their families, as well as the pilot project itself. The six sectors and their associated participant numbers can be seen in the visual opposite.

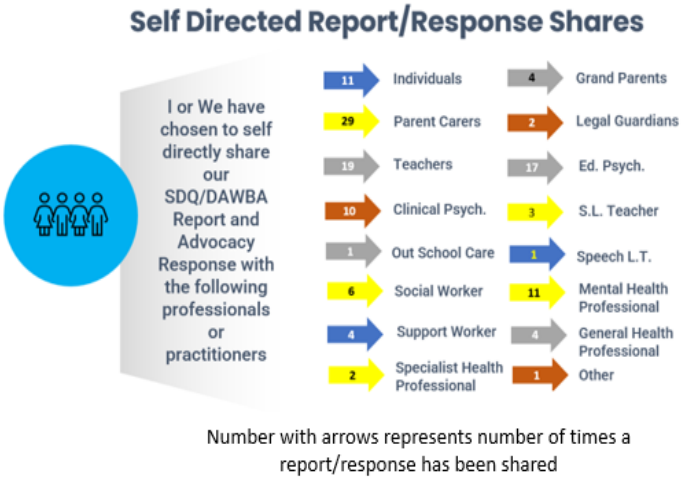


In respect to Granular Contribution the level of commitment from individuals, their parent/carer, legal guardians, to attain initial commitment from a professional to complete a questionnaire on child or young person's behalf was exceptionally promising.

Taking account of fifteen participants who drop out (29%,) equating to forty-three questionnaires issued that were not completed, - this still left thirty-one questionnaires either not started or insufficiently completed to enable a contribution. See information visual opposite.

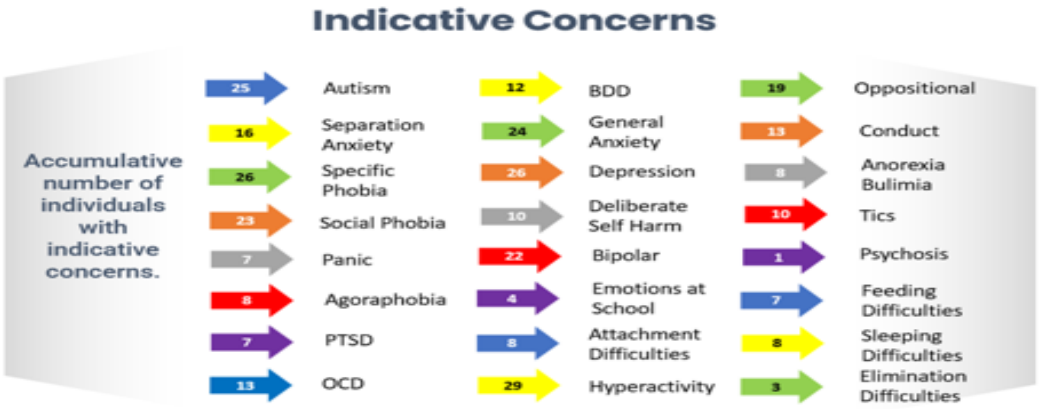
We, like families were surprised, by the fact that twenty-five educational professionals committed to individual and or parent to completing a questionnaire on an individual's behalf, supporting their assessment, yet only one third were duly completed.

Despite this negativity, for unexplained reasons, it would appear it has not deterred individuals and or parent carers
from self-directing report and advocacy responses across their networks of both professionals and non-professionals as shown on the following infographic.



Number with arrows represents number of times a report/response has been shared

From the SDQ/DAWBA Reports, we were able to identify as per infographic below, indicative concerns. Concerns sufficiently justified to the nominating partner that



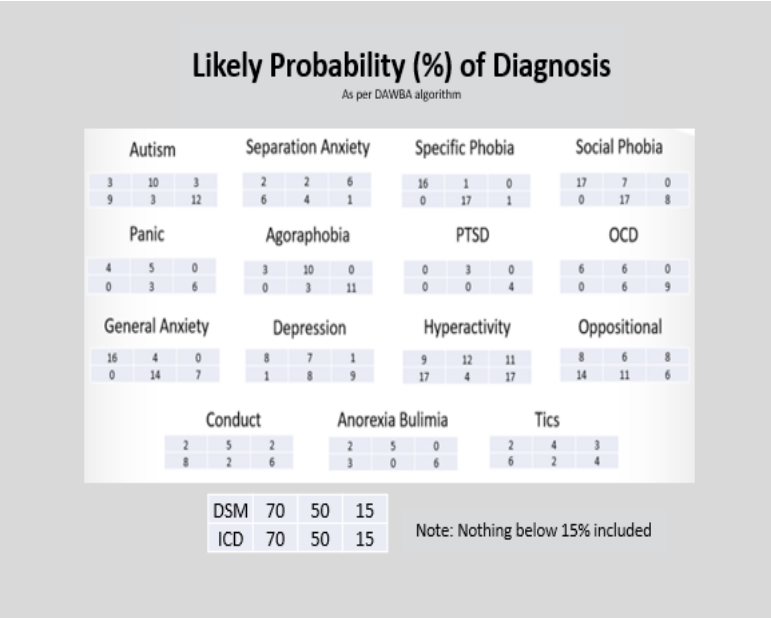
Number with arrows represents number of times a concerns has been indicated

participation in this pilot would be beneficial These are illustrative of explanations for some of the challenges and concerns being raised by either individuals, their parents/carers, or legal guardians and/or professionals with professionals.

The DAWBA algorithm, provides an indicative probability of diagnosis. The computer prediction is never an absolute "no" or "yes"; instead, the individual is assigned to one of six probability bands, ranging from less than 0.1% likely to more than 70% likely.

	Probability of Disorder
--	less than 0.1%
-	around 0.5%
-/+	around 3%
+	around %15
++	around 50%
+++	70%

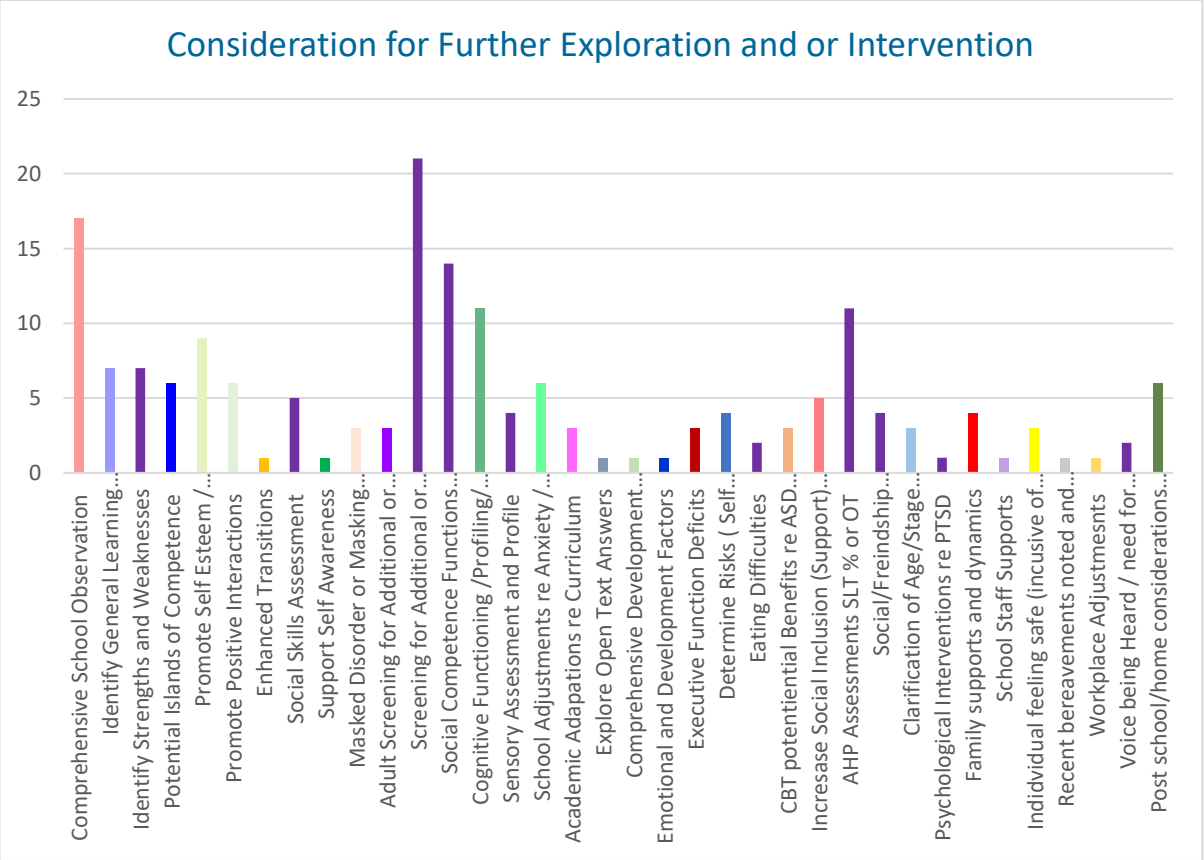
From this pilot's data, autism for example, we can deduce there is an estimated 16-24 individuals with a varying likelihood of between 15% to 70% probability of receiving a formal diagnosis.



Using the same example, one of the 'benefits' of this assessment instrument depends on the effectiveness and complimentary and supportive skillsets between the rater and clinical psychologist, in providing additional strategic insight into current and future need.

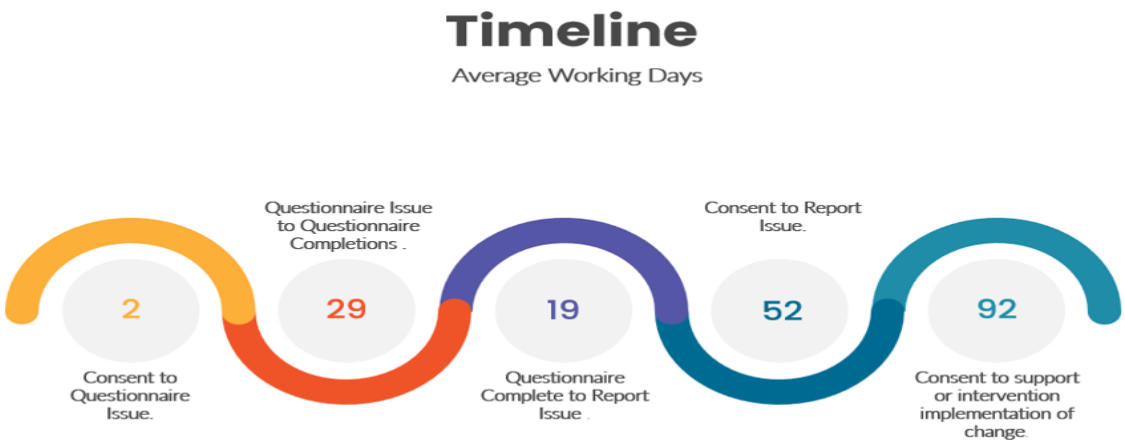
Without use of this assessment instrument, delay in any diagnostic assessments that can impact on timely interventions could be implemented by other professional disciplines.

Within the pilot, the SDQ/DAWBA reports, collectively identified and suggested as chart below, areas for considerations for further explorations and or interventions.



We learnt that we were able to engender less adversarial conversations. Whilst at the same time augment improved horizonal conversations between individuals, parent carers and professional alike, supporting input and co-created outputs into actions

As a result of this parallel multi-disciplinary inter-communicative approach our average timelines both per stage of our process and overall are illustrated in the following visual.



***Outcome*:** An average of

from consent to intervention implementation or diagnosis.

***Outcome*:** Based on suggestions for consideration from the DAWBA report and soft touch advocacy response.

partnership identified actionable rate reported.

Are we answering either of our two big questions? One can deduce statistically and in practice, the partnership approach of placing children and young people at its core, (with the one person one report ethos, and a supportive soft advocating response) is having some impact.

Included is a random selection of case studies.

Case Studies

Case Study Sample A

Summary Profile Pilot *Categorisation — Health and Education*.

Participant in this case study a resident in Central Scotland, attending a mainstream school. Despite pursuing professional diagnostic assessment for a number of issues and concerns, yet, even with professional acknowledgement. Whilst investigative assessments are underway and have been for some time, there is no assessment conclusion or definitive plan of action in terms of treatments, interventions, or support. It is for this reason, after independent advice and guidance, it was suggested, participation in this pilot project could be beneficial. Our hope is that it may provide some reassurance and steps, no matter how small, towards much requested and sought-after diagnosis and supports. Given the child's lack of development and capabilities, the online questionnaires for this assessment were completed in this instance by, mum, dad, and a family support person.

Participant Overview

With no clear diagnosis yet. This individual's growth is unusual since pre-birth, she has always been exceedingly small for her age and the family have been told that some of her features point to a genetic condition or syndrome. This may include a neuro-development disorder, a learning disability or possibly autism and that "bits of her brain are missing," as well as being informed she has the mind of a much younger child." A recent Brain scan showed some brain abnormalities and possibly something called "Temporal Cortical Hypoplasia" as well as a number of other flags, a sleep disorder, a heart murmur, Hyperacusis and Symbolic Agnosia.

This child has also experienced a lot of earache and respiratory complaints and she has constant stomach issues and bowel problems. Sleep is always difficult and more recently she has been having sleep seizures. She is waiting for a follow up brain scan under general anaesthetic and referred for an Autism Assessment (standardized screening), but the family have been told this can take 18+ months to happen.

SOCIAL AND EMOTIONAL ISSUES:
These date back to pre-school; been told she is "emotionally all over the place" She has difficulty concentrating and coping with background noise and loud noises. Too many people around her at once make her anxious. She often gets stressed and frustrated and tends to hit out and fight if there are too many children around her, she has separation anxieties and going into school causes her to get really upset. Although once she is there she usually settles down. She hates any type of change – e.g.: even a slight change of furniture or décor She is happy and affectionate child, but she is not keen on being touched, kissed, or cuddled. She also hates wearing clothes and hates dressing or being dressed and she tends to strip-off indoors whenever she can.

In 2020, it became known she has been a victim of child-on-child sexual abuse which has made her even more emotional. This individual is soon to start seeing a CAMHS worker.

LEARNING ISSUES:

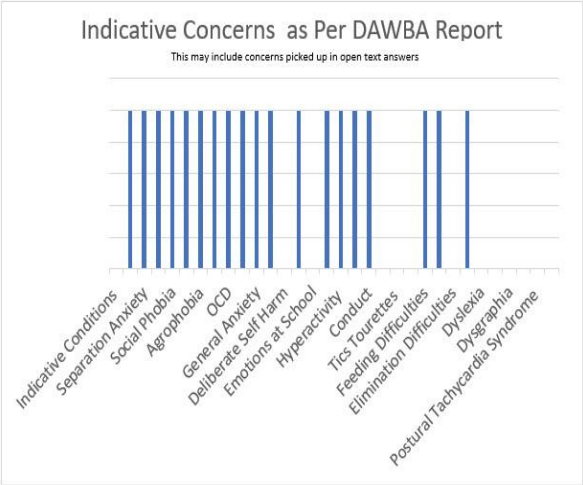
While she really loves being active, doing well at physical activity such as gymnastics and cycling and roller skating etc., she still cannot read or write or sound letters out as she struggles to read even simple words like “and,” “no” and “it “. She cannot complete quite simple schoolbook tasks such as reading, writing, drawing, craft etc., In comparison with her classmates she is well behind where she should be, having still not reached “early level” stage.

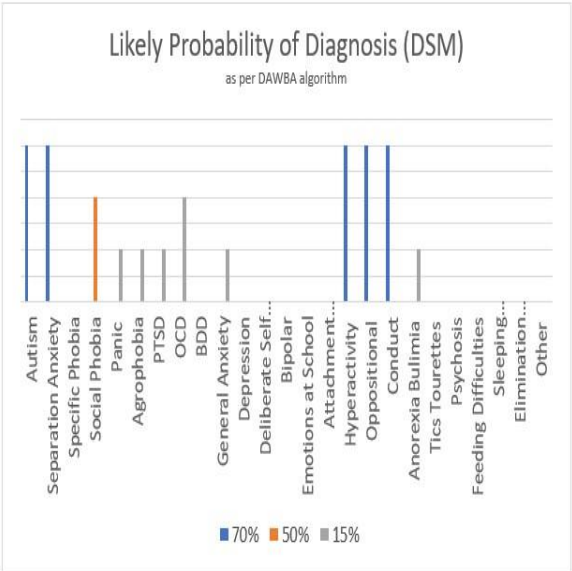
The school have only very recently started putting in some exceedingly small support strategies in for her. We have been struggling for a long time with no help.

The family from advice and guidance from Enquire and CYCPS have submitted a request for a coordinated service plan.

Development and Wellbeing Assessment Summary

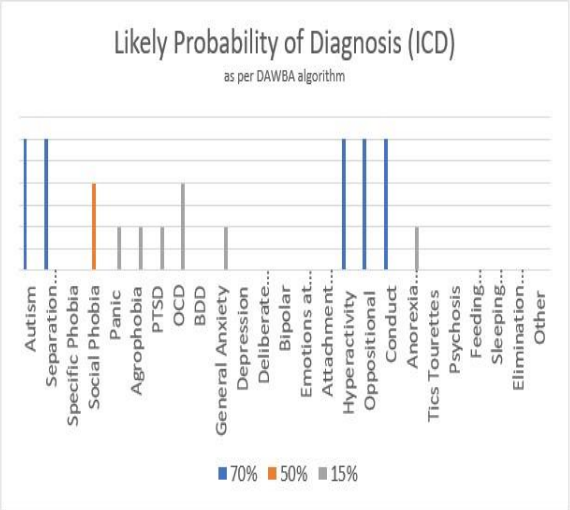
This DAWBA profile was generated as part of a Scottish Pilot Project which aims to explore the use of the DAWBA in non-clinical settings as a triage/pre-diagnostic assessment instrument. Ratings are based on the probability estimates generated by the DAWBA algorithm and are informed by open-text data from the respondents. They are not to be regarded as concrete ‘diagnoses’ but ‘working hypotheses’ to assist in planning and decision-making. Complex profile with reasonable consistency between respondents. Medical concerns noted in terms of impact on young person (YP) and family. Possible chromosonal atypicality noted.

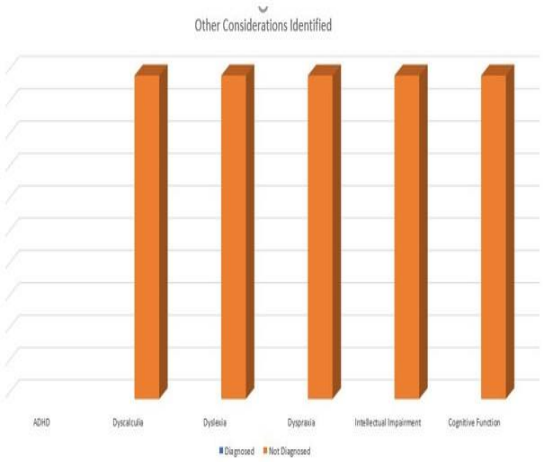




Further assessment may benefit from multi-disciplinary diagnostic service viz differential dx. High probability of neurodevelopmental disorder and comorbidity. Autism risk identified with key diagnostic criteria met for full assessment (e.g., ADIr/ADOS). As a pervasive developmental disorder, ASD risk may support intervention decisions re other areas of need, including post-trauma support. Specific processing needs of ASD clients

should be considered when attempting any generic support (e.g., CBT). ASD risk informs understanding of possible contributory factors viz separation anxiety, specific and social phobia, generalised anxiety, and 'ODD' and conduct 'disorder'. ODD and CD not currently rated for this reason - i.e., that behaviours may be explained better in terms of autistic regigidities and needs rather than as discrete disorders per se. Biploar over-





ruled due to age/stage and lack of evidence of true elevated mood rather than hyperactive episodes. ADHD indicated.

Academic difficulties noted and suggestive of potential benefits of assessment for specific learning difficulties (e.g., dyslexia/dyscalculia/dysgraphia) and cognitive function. Assume vision and hearing have been assessed as 'normal'. If not, testing may be of benefit. Intellectual +/- developmental delay?

Suggestions: 1) Differential diagnostic assessment with focus on genetic and neurodevelopmental contributions to needs profile. 2) OT assessment re sensory profile and possible development of 'sensory diet' to minimise stress. 3) SALT assessment to determine receptive and expressive language capacity. 4) Communication passport based on SALT assessment to assist YP in communicating with adults and peers. 5) Cognitive assessment to determine current level of function (both at home and at school) and reasonableness of age/stage demands being made of the YP. 6) Academic adaptations to curriculum and environment (sensory/attentional challenges + social demands) 7) Psychological interventions re post-traumatic support to be informed by idiosyncratic processing needs of a (potentially) autistic YP 8) Support for the family in terms of understanding contradictory needs for 'sense of safety', structure and routine, as well as stimulation and challenge. Help to identify triggers and to de-escalate meltdowns. 9) Support for school staff in terms of understanding YP's complex needs and vulnerability. Emphasis of helping YP to feel safe with respect to environment and relationships.

Advocacy Response

The demonstrates multiple and complex pre-diagnostic probability with working hypothesis suggesting the likelihood of syndromic diagnosis, thus highlighting the current overarching challenges that the child, her family, and practitioners and professionals collaborating with her are facing.

Based on the information available and consideration of the key questions. (See below.)

Key Question Note answers are based on info currently available	Yes	No
Is the family doing all they know how to or with advice and guidance attempting to do the right thing re their child's assessments and interventions	✓	
Does the child have complex or multiple needs which have a significant or adverse effect on his/her learning?	✓	
Does the child have Additional Support Needs?	✓	
Will the Additional Support Needs of the child last for more than a year?	✓	
Do the child's Additional Support Needs require a significantly high level of co-ordinated input to educational planning from one or more agencies in addition to Education?	✓	
Is there in a need for substantial and significant additional support provided by Education at a Level 3 Continuum of Support model?	✓	
Does the child have a detailed Child's Plan? Not that we have been made aware of.		✓
Is the Education Authority responsible for the education of the child or young person?	✓	
Would the child, the parents and front line educators and support staff benefit from input from allied health specialists associated to child's needs?	✓	
Is there a need for potential further exploratory assessment by appropriate specialists?	✓	
Would the child benefit in the short, medium or longer term, from one of the following – Child's Plan, Coordinated Service Plan, Staged Intervention Plan, Individualised Educational Programme, Personal Learning Plan ? https://education.gov.scot/parentzone/additional-support/how-schools-plan-support/types-of-plan/#:~:text=Co%2Dordinated%20Support%20Plans,-This%20statutory%20plan&text=Your%20child%20may%20be%20eligible,non%2Deducation%20service%20or%20agency	✓	
Would both advocacy support and further parental support be beneficial for child and her family?	✓	

We would strongly suggest assisting in planning and supportive decision making, strong advocating support for a plan, with an overall focus on GIRFEC and the SHANARRI components.

It is, however, more the content of a good plan that is significant rather than the type.

There are many ingredients and inclusions in making a good plan. https://www.autismnetworkscotland.org.uk/documents/view/c356b7c5-143a-48b5-92c9-df2e09e1b146

Delivery of direct advocacy provision is not part of the pilot. In this instance we signposted

to two advocacy organisations, where acceptance and access may/will be subject to eligibility criteria.

Delivery of direct advocacy provision is not part of the pilot. In this instance we signposted to two advocacy organisations, where acceptance and access may/will be subject to eligibility criteria.

In consideration of a good plan, this may include some or all the following and more depending on further assessment:

- Outcome focussed to benefit the individual, make targets achievable and measurable
- Undertaking of further assessment and identification
- Ensure holistic education and social development both in and out of school
- Encompass the individual as far as capacity enables in the development of their plan to the best of their own capability (provide supportive advocacy if required) (use supportive communication tools if appropriate)
- Take account of hidden sensory issues often a key trigger for meltdowns, a trigger and solution analysis may be helpful.
- Have an initiative-taking partnership approach which includes individual, parent/carers, practitioners
- Be inter-agency connected, health, social care, including third sector clubs etc. if appropriate

As we all know beneficial outcomes for an individual are based on positive collaborative partnership working, including between parents and professionals and professional to professional. We would suggest this is critical in this instance to enable joint delivery of suitable and timely interventions to meet the individual's needs.

Feedback and Actions Taken.

"We were delighted to have been referred to this pilot via a legal professional who works within children's rights. We found the questionnaire's challenging and very thorough." Parents

"As parents we found it very reassuring that we were aware of our daughter's complex challenges. The report confirmed that we needed support, further assessment, and explanations, not just for us, but for the professionals that also collaborate with our daughter."

"The soft advocacy response empowered both of us as parents, our daughters support practitioner and teacher to advocate better for our daughter's needs."

"Our hope and objective were to encourage more meaningful joined up person centred approach in relation to education health and social inclusion and to improve a joined up working practice to enable more focused discussions in our daughters TAC meetings, reducing conflict both between professionals, and professional practitioners and us parents."

"We shared the DAWBA report and explanation leaflet with the following professionals -- Teacher, Head Teacher, Educational Psychologist, GP, CAMHS, associated AHPs, and with local authority Inclusion, ASL and Needs Service Manager."

"It has taken us a long time to get this far, and it is too early to state what will actually be put in place to support and bring about improved outcomes."

"We felt there could be improvements by the a) questionnaires could have supportive visuals or explanation videos, b) an advocacy professional could hold responsibility for accountability and coordination of information flow associated to progress via TAC meetings."

"We appreciated the referral to an advocacy service. We did not get advocacy. We got some family support to help us at TAC meetings and with communications with professionals and service managers. Too early in practice to determine the direction of actions."

"Thank you for enabling us via this pilot."

Observationally, this family and their professional partners can envisage actions if implemented having a positive impact of delivery within the following policy areas –

- *Getting it Right for Every Child,* [7]
- *The Promise* [23]
- *The Accountability Gap* [24]
- *All Our Children All Their Potential* [5]
- *The Additional Support for Learning Action Plan (ASLIP)* [25]
- *The Neurodevelopmental Specification: Principles and Standards of Care* [29]
- *United Nations Convention on the Rights of the Child* [9]
- *The Equality Act.* [30]

and more.

Case Study Sample B

Summary Profile Pilot *Categorisation —Further Education/ Employability/Social Care.*

The participant in this case study is a young adult, resident in Central Scotland, part time college, and in receipt of SDS Package. Despite pursuing employability options for the last 3 years, nothing has transpired to date. This young person and his family hope that participation within the pilot may bring some cohesion and better understanding of the young person to the fore to enable accessibility to with reasonable adjustment to inclusive opportunities.

Participant Overview.

I am a 22-year-old young adult who has autism. I struggle with social situations and require constant prompting to behave appropriately. I love people; however, I find friendships exceedingly difficult. I say inappropriate things and say things that people find rude and upsetting. I am unaware of dangerous situations and have no sense of stranger danger, so I speak to everyone and think that everyone is my friend. This makes me very vulnerable, and I was arrested a few years ago and had to go to Govan police station. This was a very frightening and scary time for me. I only spoke to the lady and was trying to be friendly.

My anxiety levels can escalate very, very quickly. I struggle with time and if I do not do something at a certain time, I can become frustrated and angry. I require support to keep calm and stay on a green I require this support everyday several times a day.

I have no concept of money. I love to shop, and I can open an eBay account as a guest. This has got me into a lot of trouble with my mum as I bought a few trains at £225.00 each. I am trying to work on having a better understanding of money and trying to learn how to budget. This is extremely challenging for me and |I get frustrated when I have spent my weekly allowance .I search for the bank cards when my mum goes to bed or goes out into the garden .I want to go on a plane next year if I am well enough so I know I will need to save for this .

I live at home with my mum and my brother. I would like to live on my own when I am older. Mum came over to my house and I can make her dinner. My brother and his girlfriend can also visit me. I love my family very much and enjoy the family parties that we have. I love when my mum's friends come over.

I really enjoy the club one evening a week. I get to see my friends there and we have lots of fun.

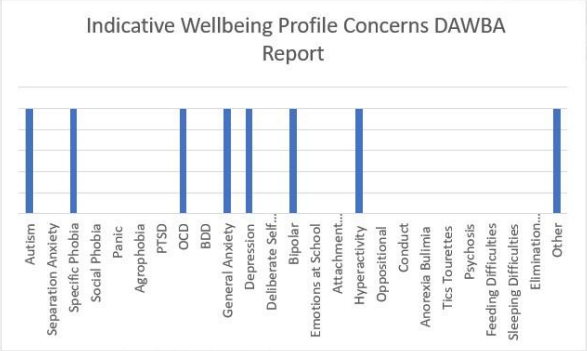
We chat and laugh. We also support each other if any of us are struggling with things at college or at home.

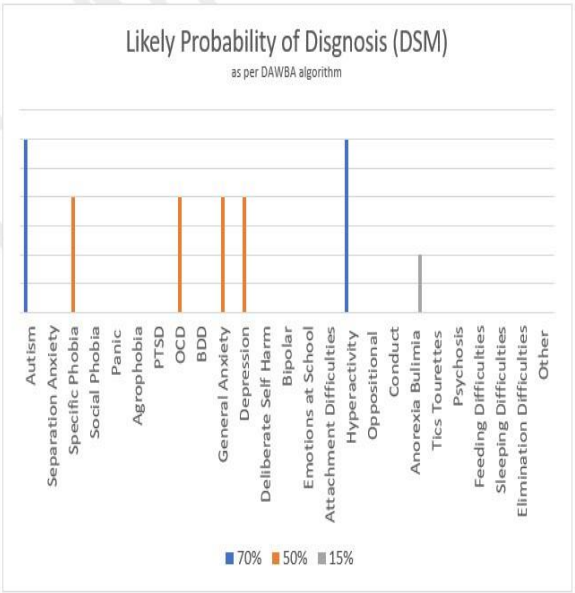
This participant disclosed two previous diagnoses, autism and learning disability.

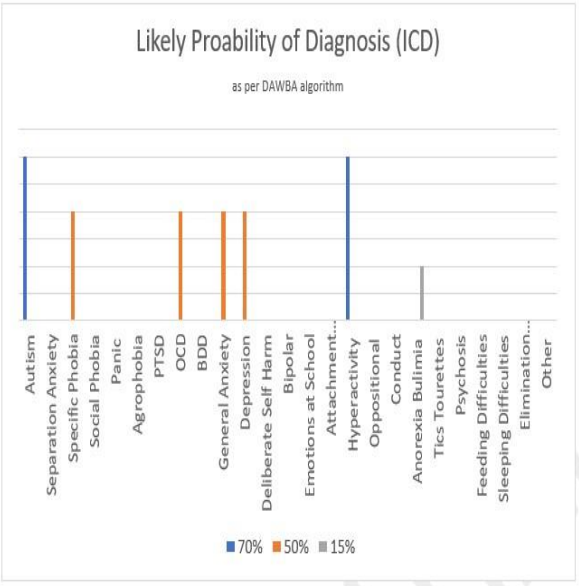
Development and Wellbeing Assessment Summary

Autism. Other consideration depression, ??Mania/bipolar??ADHD combined.

Consistent responses from self and parent/carers supported by open-text information. Autism diagnosis appears secure and may explain specific and generalised anxieties, social communication and interaction difficulties, and routines/obsessions. OCD not discounted but main intrusive feature appears to be associated with time rather than discomfort in the activities/thought patterns per se. Worth exploring further. Impact of life events noted and especially loss of grandparent. Associated with onset of depressive features in profile. Possible unresolved issues around bereavement viz impact on family routine and personal interactions. Bip/ADHD worth exploring further and specifically nature of elevated mood v hyperactivity. Auditory hallucinations noted. No current evidence of self-medication but possible unmet need re mood. Also explore potential dysregulated sleep and impact on daily function. Pattern/severity etc. Treatment options could be informed by ADHD/Bip Dx and assessed alongside current treatment programme. DAWBA profile supports further investigation and potential differential Dx for comorbidities common in ASD population.







Advocacy Response

Given this young person DAWBA report and Participant Overview both complementary to one another demonstrates a number of probability factors with working hypothesis.

In this case one may consider advocating for further investigations as indicated within the DAWBA report as well as consideration for occupational inclusion and bereavement support via for example-

a) Sharing the DAWBA with his Psychiatrist or Psychologist
b) Employability or further programmes at college.
c) Seasons for Growth programme to support his bereavement understanding.

It may also be worth considering supporting DM to complete a My Autism Profile to help him understand his own condition. My Autism Profile
https://www.southlanarkshire.gov.uk/downloads/file/13763/my_autism_profile

It is also our understanding that this young person is entitled to Independent Advocacy under current mental health legislation re his autism. Search the SIAA
https://www.siaa.org.uk/find-an-advocate/

Feedback and Actions Taken.

"We found the questionnaires comprehensive and thorough. Being online was a big benefit as one could log in and out completing in sections as need be. Supporting processing."

"Would suggest increased visuals.

Would suggest consideration of making it an app as oppose online questionnaire thus enabling improved ease of use."

"We felt it could be useful to have a stronger component re environmental and sensory challenges/concerns."

"We found the report fully accurate and informative, and it noticed some underlying concerns we felt could be there. Concerns over and above already diagnosed autism and intellectual disabilities."

"My sons and I self-directly shared the report with my son's psychiatrist and used it to support our underlying concerns. We also used the report to support our actions in respect of his self-directed support provisions."

Has it help to attain targeted service to support you and or tailored supports for you? Please cross all that are applicable or appropriate.

Target / Tailored Provision	Cross all Applicable
Comprehensive School Observation	
Identify General Learning Profile/Plan	
Identify Strengths and Weaknesses	x
Potential Islands of Competence	
Promote Self Esteem / Reinforcement of success	
Promote Positive Interactions	
Enhanced Transitions	
Social Skills Assessment	x
Support Self Awareness	
Masked Disorder or Masking weaknesses	x
Adult Screening for Additional or Differential Assessment re DX	x
Screening for Additional or Differential Assessment re DX	
Social Competence Functions /Language SPLD/Comms Passport	
Cognitive Functioning /Profiling/ Match to Attainment	
Sensory Assessment and Profile	
School Adjustments re Anxiety / Demand Led Challenges	
Academic Adaptations re Curriculum	
Explore Open Text Answers	x
Comprehensive Development Disorder Factors	
Emotional and Development Factors	
Executive Function Deficits	x
Determine Risks (Self Harm/Substance/Sexual)	
Eating Difficulties	
CBT potential Benefits re Anxiety/OCD	
Increase Social Inclusion (Support) and QOL v Attainment Goals	
AHP Assessments SLT % or OT	
Social/Friendship Inclusion and Development	x
Clarification of Age/Stage expectations/supports	
Psychological Interventions re PTSD	
Family supports	x
School Staff Supports	
Individual feeling safe (inclusive of social fears)	
Recent bereavements noted and support options explored	
Workplace Adjustments	
Voice being Heard / need for trusted adult	x
Post School Planning	
Reasonable Adjustment in Employment	x
Improved Individualised Employment Placement	
Disabled Student Support Application	
Other	

"My sons psychiatrist found the report informative and used it as a supportive guide in his considerations re further assessment."

Through our family's equity level discussions with professionals, we envisage the on-going actions positive impact on and of delivery within the following policy areas –

- *Getting it Right for Every Child,* [7] *[if this was done whilst still within education]*
- *The Promise* [23]
- *The Accountability Gap* [24]
- *All Our Children, All Their Potential* [5]
- *The Additional Support for Learning Action Plan (ASLIP)* [25]
- *The Neurodevelopmental Specification: Principles and Standards of Care* [29]
- *United Nations Convention on the Rights of the Child* [9]
- *The Equality Act* [30] *and UNCRPD* [31]
- *The National Mental Health Strategy 2017-2027* [32]
- *The COVID Recovery Strategy – A Fairer Future* [33]

and more

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

Case Study Sample C

Summary Profile Pilot *Categorisation —Education/CAMHS*

The participant in this case study is a young adult, currently progressing through high school and experiences difficulties with social communication and interaction and inflexibilities that impact her daily life.

Participant Overview.

I am a 14-year-old girl, in my second year in high school. I live at home with my brother, sister, mum, and two dogs. I have always had problems with noise as long as I can remember. I cannot cope with loud noises like banging, shouting etc. I have trouble getting to sleep most nights, sometimes rocking myself to sleep. Mum says I have been like this since I was a baby.

I do not cope well with changes and find it hard to work up the motivation to do things sometimes. Finding school difficult as there are so many people and so much noise that it overwhelms me. I get incredibly stressed out and anxious about it.

I fond friendship a struggle too as I often think my friends do not like me or find me annoying as I often do not understand what they mean, sometimes by their actions or by what they say. I sometimes get upset and think it would be better if I were not here because of the way my thoughts are.

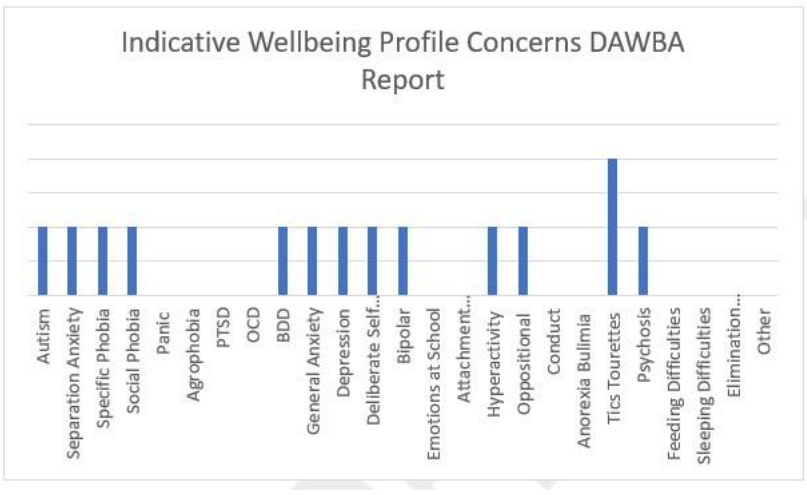
I also have tics which I cannot control, and I do not know how to stop them either.

I struggle to concentrate for extended periods of time, feeling as though I forget things quickly, especially if I need to carry out a few instructions one after the other.

I get angry and stressed out at trivial things.

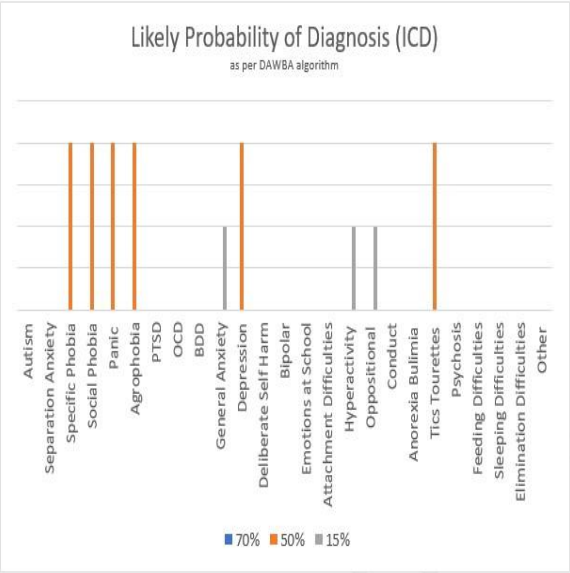
Development and Wellbeing Assessment Summary

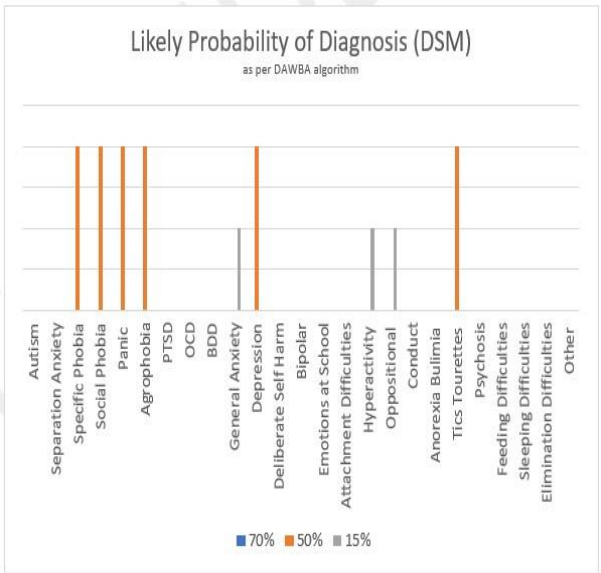
General profile is of a young female with elevated levels of anxiety, low resilience, and currently depressed. Discrepancy between self and parent symptom reports is not unusual. Specific and social phobia noted and rated accordingly. Insufficient data for ASD to be considered an elevated risk, but subtle indications of difficulties with social communication and interaction and inflexibilities warrant further investigation. Presence of both motor and vocal tics suggestive



of TS (or similar) and thus of underlying NDD contribution to presentation. Strengthens relatively weak evidence base for attention disorder and supports parental comments re weak executive function and organisational skills. Understanding of female ADHD phenotype may help with further assessment and understanding of difficulties.

Further investigation into social understanding and communication skills, and collateral information on learning and behaviours (esp. social interaction) would help. Quantitative info on extent and quality of peer relationships would support formulation. Sensory difficulties? Worth exploring to establish full range and impact. Unclear whether true mania or pro-dromal psychosis are present. Responses suggest not, but vigilance necessary. Suggestions for considerations: 1) Holistic assessment considering both emotional and developmental contributory factors (esp. tics), 2) Further information on current academic attainment and cognitive performance, 3) School observation with focus on social function and social skills, 4) Short sensory profile to establish extent, if any, of sensory difficulties (with possibility of sensory diet to alleviate stress), 5) Strengths-based approach to building peer relationships and self-esteem, 6) Availability of 'trusted adult' with whom she can communicate her concerns





Advocacy Response

This young person's DAWBA report demonstrates a number of indicative possibilities, which one would suggest following up on. Treatment to help control TICs can have impacting benefits on an individual confidence with potential positive knock on to other aspects of life.

In her case one may consider advocating for further investigations as indicated within the DAWBA report as well as consideration for additional support via

a) Sharing the DAWBA with her GP for further referral or psychologist for further assessments. Risk has been identified re suicidal planning.

b) Consider the use of Handicalender https://www.abilia.com/en/our-products/cognition/memoryand-calendars/handicalendar, could be supportive app for remembering.

c) Explore options or access to befriending or support provision.

d) If she thinks her voice is not being heard at school perhaps one could approach My Rights My Say.

Disclaimer - The above is based on the outcomes of the Development and Well Being Assessment and the Participant Overview. It has been issued for consideration and suggestion. It is up to the individual, subject to capacity, the parents/carers, legal guardians, in partnership with practitioners and professionals to decide and determine what actions are taken if any going forward.

Feedback and Actions Taken.

"We found the questionnaires comprehensive and thorough."

". Our daughter found it very helpful she felt included about her, for her. Enabling those who supported her to be more informed and do a better job."

"Would be used to have more pictorial supports.

Provision of telephone support."

"Opportunity to have a stronger component re environmental and sensory challenges/concerns."

"We shared our daughters report with her key teacher, headteacher, GP. CAMHS. And other Allied Health Professionals."

"As parents it was very 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 ended up leaving school with no supports. "

"The report and advocacy response empowered our daughter, ourselves as parents, and her key teacher to advocate better for our daughter's needs."

"It already has, it has changed the whole outlook of the TAC meetings they are more inclusive, especially of taking our daughters views into consideration. We are fully supportive of this process now, whereas before it was a constant battle."

Table re Suggestion for Consideration and Self-directed Partnership Identified areas of action

Target / Tailored Provision	**Cross all Applicable**
Comprehensive School Observation	
Identify General Learning Profile/Plan	
Identify Strengths and Weaknesses	**X**
Potential Islands of Competence	**X**
Promote Self Esteem / Reinforcement of success	
Promote Positive Interactions	**X**
Enhanced Transitions	
Social Skills Assessment	
Support Self Awareness	
Masked Disorder or Masking weaknesses	**X**
Adult Screening for Additional or Differential Assessment re DX	
Screening for Additional or Differential Assessment re DX	
Social Competence Functions /Language SPLD/Comms Passport	
Cognitive Functioning /Profiling/ Match to Attainment	**X**
Sensory Assessment and Profile	
School Adjustments re Anxiety / Demand Led Challenges	**X**
Academic Adaptations re Curriculum	
Explore Open Text Answers	
Comprehensive Development Disorder Factors	
Emotional and Development Factors	
Executive Function Deficits	
Determine Risks (Self Harm/Substance/Sexual)	
Eating Difficulties	
CBT potential Benefits re Anxiety/OCD	
Increase Social Inclusion (Support) and QOL v Attainment Goals	
AHP Assessments SLT % or OT	
Social/Friendship Inclusion and Development	**X**
Clarification of Age/Stage expectations/supports	
Psychological Interventions re PTSD	
Family supports	
School Staff Supports	**X**
Individual feeling safe (inclusive of social fears)	
Recent bereavements noted and support options explored	
Workplace Adjustments	
Voice being Heard / need for trusted adult	**X**
Post School Planning	
Reasonable Adjustment in Employment	
Improved Individualised Employment Placement	
Disabled Student Support Application	
Other	

"Guidance and Support for learning teachers took note and actioned accordingly, especially associated to daughters' anxiety, which impacts across all her daily life."

Through TAC discussions as actions are implemented it could be having positive impact of delivery within the following policy areas –

- *Getting it Right for Every Child,* [7]
- *The Promise* [23]
- *The Accountability Gap* [24]
- *All Our Children All Their Potential* [5]
- *The Additional Support for Learning Action Plan (ASLIP)* [25]
- *The Neurodevelopmental Specification: Principles and Standards of Care* [29]
- *United Nations Convention on the Rights of the Child* [7]
- *The Equality Act* [30] *and UNCRPD* [31]
- *The National Mental* Health *Strategy 2017-2027* [32]
- *The COVID Recovery Strategy – A Fairer Future* [33]

and more

"Thank you for enabling us to be part of this pilot." "Know me better - Enables us all more."

"This assessment approach should be used for more young people who are struggling."

Case Study Sample D

Summary Profile Pilot *Categorisation —Education*

This is young male resident in Scotland, transitioning between secondary with a number of challenges that are impacting on his daily life, while waiting for assessments.

Participant Overview.

This young person has a range of different difficulties which are educational and developmental. In Primary 5 he was assessed by Speech and Language Therapy due to concerns mum had over his understanding of words – hearing words and then repeating them back differently, and word recall issues. The school were initially very resistant to this as he is articulate and can talk fine. However, SaLT came back with a language disorder which has not been catered for by his high school. Negative cycle focusing on behaviour at school for all of first year at high school. This has led to mental health and self-esteem issues and a lack of relationships between him and others. Relationships have always been particularly important to him.

He also has dyslexia. He is not keen to be seen as different to others. However, at the point of filling this page out, he is realising that he is different to other people and that he does not know why.

He is showing concerning traits around social situations. He is mirroring behaviour that he is seeing e.g., other teens using the same words leads to him using the words even when he does not know when to use them or what they mean. At times he seems worried about looking stupid and therefore will keep speaking when there is some sort of disagreement with friends or adults. This is leading to issues with adults in and out of school. He then fixates upon how a situation was for him and struggles to see other viewpoints. He struggles to maintain friendships because he needs constant reassurance in friendships. When having conversations back and forth with friends, he can take it too far, or take things very personally.

When something goes wrong, he seems incapable of being able to deal with it and will have a meltdown. Meltdowns are caused by him struggling to communicate things or not being sure what to do next, from the bread being mouldy, to fall out with friends. It will not always be clear why he is having a meltdown.

He fears violence due to experiences with domestic abuse (not directly) when he was younger and counselling, he had for that. This has led to him panicking when there are violent fights at school. He may become very hyper after them and has explaining that he feels scared, and he is not sure how to behave when he feels like that.

He really struggles with doing things there and then and will try and say ‘later’ so a task is delayed until a future point. It is like he does not know how to start a task, he tends to panic and become frustrated. If asking him an open question, he struggles. Metaphors are difficult for him – he thinks they are strange. He is very literal. Has issues seeing things from the perspective of others without support e.g.one group of teenagers at school walking about

with pride flags telling him to go and kill himself because he is not gay leads him to think everyone who is gay behaves like this. He fixates on things he is interested in and needs others to understand why something is important to him there and then.

He has OCD tendencies, low self-esteem, a tendency to lean towards disordered eating, especially when he is feeling unsecure/unsafe.

As parents we are struggling to get the correct supports in place for him.

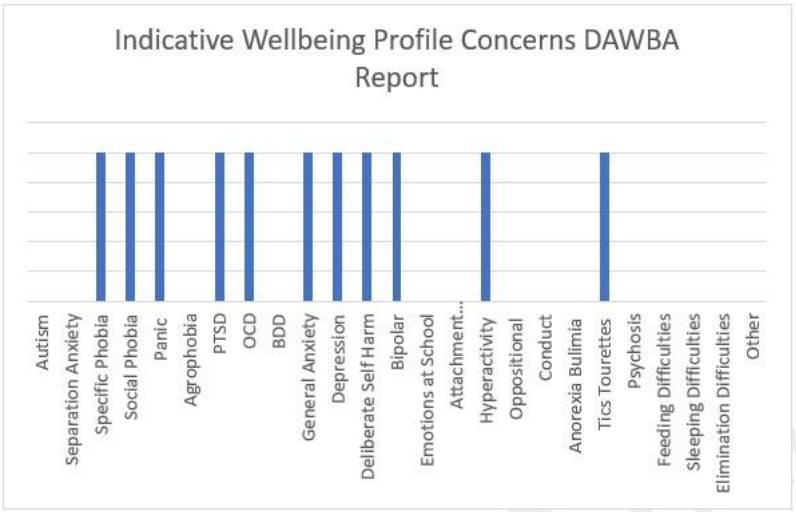
Development and Wellbeing Assessment Summary

Tourette ADHD combined OCD Generalised anxiety ??PDD/Autism

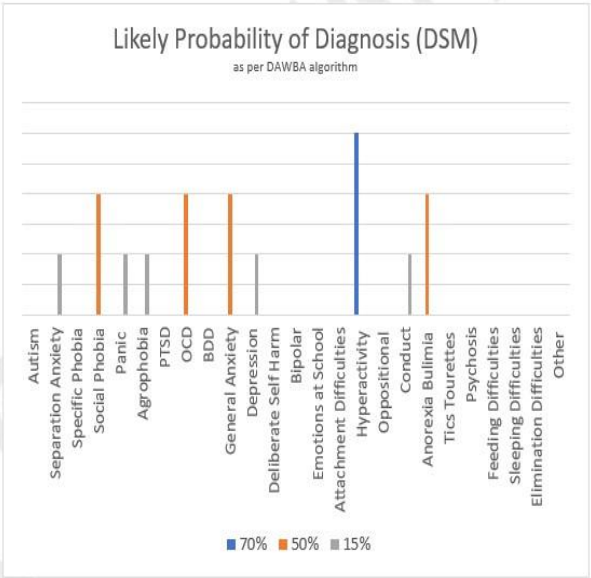
Profile of a young person ill-at-ease in educational setting. Reasons unclear but appear to be associated with both academic under-performance, difficulties in interacting with adults and peers, and problems with self-regulation.

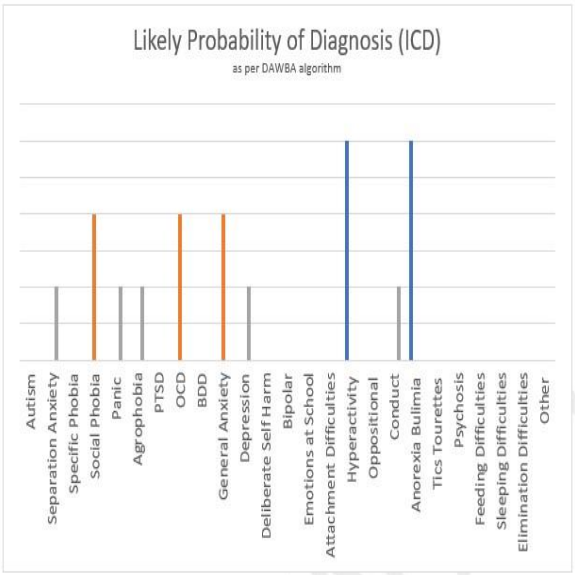
Uncertainty around cause of heightened anxieties and direction of causation between these and other difficulties (e.g., hyperactivity/OCD). Both developmental and emotional disorders appear to be evident. Possibility of ASD remains despite insignificant risk indicated. ADHD indicated and supported need for further assessment in both school and home domains. Profile would benefit from detailed school observation and examination of social understanding and academic functioning (i.e., does he have the social kills and understanding but is unable to access them? YP may be struggling with curricular demands if cognitive functioning below that of peers. Also, likely to have difficulties with executive functions (time management, personal organisation etc. Open text answers support involuntary nature of many observed behaviours and thus challenge with self-management in certain situations. A cognitive assessment may help school staff to understand YP's difficulties with task completion and classroom behaviour.

Also, worth exploring SpLDs other than dyslexia. It is evident that he is hyperaware of how others perceive him and as such the response from all adults collaborating with him will be vital in supporting him, particularly in relation to behaviours that he has no control over. Negative responses such as 'telling off' or drawing attention to him in a classroom setting will perpetuate his anxiety and exacerbate the behaviours. If staff are aware of his engaging in movements or vocalisations, we would recommend that they check in with him in a supportive way. Interviews provide support for further examination of both OCD and Tic Disorder. Overall complexity of profile suggestive of need for



differential assessment to tease apart causal links and to discriminate any underlying NDDs from contribution of emotional factors. Risk of attributional uncertainty and 'explaining' range of behaviours by reference to low cognitive ability rather than pervasive disorders. YP might benefit from: 1) Detailed school observation, 2) SALT assessment (esp. re social understanding and communication), 3) NDD (including ASD and ADHD) assessment, 4) Cognitive assessment, 5) Additional support in class and during unstructured periods in school day (social support), 6) Child's Plan or Learner Profile to support school staff in understanding YP's difficulties, 7) (Depending on outcome of the above) a differentiated curriculum, 7) Differential dx.





Advocacy Response

This DAWBA report demonstrates a number of factors and probabilities with working hypothesis to assist in planning and decision making, suggesting the likelihood of conditions, for example, ADHD, OCD, and potentially ASD.

In this case one should consider advocating for further investigations as indicated within the DAWBA report as well as consideration for and of and their appropriateness in compliance with for example ASL, UNCRC, and Equality -

a) Sharing the DAWBA with his GP for further referral or psychologist for assessments
b) Sharing with allied health professionals in particular Speech and Language. Perhaps the development of communication protocol for him.
c) Sharing with school to support appropriate inclusion into an integrated multi-disciplinary plan of action.
d) Supporting his inclusion in and understanding of plan – See link https://www.autismnetworkscotland.org.uk/documents/view/e89f18ff-a89e-46b8-98bc-97146b093bff
e) Given the indications from the DAWBA in supporting him it may be beneficial for him to complete 'My Autism Profile' copy attached, as this will help support him in

understanding himself as well identifying further assets which can be built on together.

f) Consider target that are achievable in small components and how they are measurable to enable him, so he can see, feel, believe, and understand for himself that he is making progress, building confidence, resilience, and capability.
g) Consider reasonable adjustments for example environment and learning.
h) Independent Advocacy via My Right My Say for educational matters -- https://www.partnersinadvocacy.org.uk/my-rights-my-say/
Or via Central Advocacy Partners
http://centraladvocacypartners.org.uk/Default.aspx

From experience of advocating for many individuals and families, with a positive partnership approach and all on the same page person centre individual first approach with cohesive strategies supporting SHANNARI principles, the outcomes for everyone have a greater chance of achievement.

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Feedback and Actions Taken.

"It was challenging as the wording seemed to contain double negatives. However, the main challenges related to my son's difficulties e.g., if a question asked, 'Do you feel sad, angry or down?' he would only be able to consider one of those options and would answer based upon this. This makes it hard when the answer is no."

"I know that the NHS assessments are remarkably similar. It would be advantageous if a SaLT could be commissioned to resign the forms use across the board."

"We have shared report with School, SaLT, Ed psych, pupil support and GP and with CAMHS. It highlighted potential diagnoses which could then be investigated in more detail."

"We did find that CAMHs were unprepared to accept the findings of the report because it did not fit within their referral process e.g., it came from the GP and not the school. This is a flaw within CAMHs as opposed to an issue with the report."

Table re Suggestion for Consideration and Self-directed Partnership Identified areas of action

Target / Tailored Provision	**Cross all Applicable**
Comprehensive School Observation	**X**
Identify General Learning Profile/Plan	**X**
Identify Strengths and Weaknesses	**X**
Potential Islands of Competence	
Promote Self Esteem / Reinforcement of success	
Promote Positive Interactions	
Enhanced Transitions	
Social Skills Assessment	
Support Self Awareness	**X**
Masked Disorder or Masking weaknesses	
Adult Screening for Additional or Differential Assessment re DX	
Screening for Additional or Differential Assessment re DX	**X**
Social Competence Functions /Language SPLD/Comms Passport	**X**
Cognitive Functioning /Profiling/ Match to Attainment	**X**
Sensory Assessment and Profile	**X**
School Adjustments re Anxiety / Demand Led Challenges	**X**
Academic Adaptations re Curriculum	**X**
Explore Open Text Answers	
Comprehensive Development Disorder Factors	
Emotional and Development Factors	**X**
Executive Function Deficits	**X**
Determine Risks (Self Harm/Substance/Sexual)	
Eating Difficulties	**X**
CBT potential Benefits re Anxiety/OCD	
Increase Social Inclusion (Support) and QOL v Attainment Goals	
AHP Assessments SLT % or OT	
Social/Friendship Inclusion and Development	**X**
Clarification of Age/Stage expectations/supports	
Psychological Interventions re PTSD	
Family supports	
School Staff Supports	**X**
Individual feeling safe (inclusive of social fears)	**X**
Recent bereavements noted and support options explored	
Workplace Adjustments	
Voice being Heard / need for trusted adult	**X**
Post School Planning	
Reasonable Adjustment in Employment	
Improved Individualised Employment Placement	
Disabled Student Support Application	
Other	

"It did to a certain extent, reduce adversarial conversations.

It was still seen as 'undiagnosed' which should not be an issue in Scotland, but it was.

A rights-based approach, as we incorporate the UNCRC into Scots law at the beginning of 2023, could provide increased opportunities for this pilot project to help increased children and young people. Crucially, it could be used to ensure public bodies/local authorities/Scottish Government are recognising their duties in terms of those with ASN and SEN."

"The pilot identified many unmet needs that had not been highlighted before. It was the gateway to my son getting the support he required. While resources at LA and school level are still problematic, the school now know what the unmet needs are – ***something we would not have achieved without this pilot."***

"It led to us getting further assessments which would not have been considered without this pilot. If we had not been lucky enough to hear about this pilot and be accepted onto it, my son would have been excluded from school."

"I wish <u>All</u> young people had access to this project. I feel this should be central to assessing unmet needs in school and helping schools (and parents) get the resources they require." Parent/Professional

Case Study Sample E

Summary Profile Pilot *Categorisation —Education/CAMHS*

The participant in this case study is a young adult female resident currently attending mainstream high school. This young person and her family hope that participation within the pilot may bring better understanding of the young person to the fore to enable more targeted supports to meet the young person's needs – collaborating with family and school.

Participant Overview (own words)

High pain threshold – has hurt oneself numerous times badly and does not seem to feel it. No temperature control jumpers on in the hot weather, wanting to go to school in a shirt when its freezing outside. Casual comfortable clothing is favourite.

Avoids social inclusion as far as possible, for example if family are over, she will stay in her room and does not want to come down. Has a singular friend from high school. Used to go to clubs, swimming, art, coding, when she was younger as I sent her. She would protest about going to clubs a lot, but I wanted her to mix and have something social to do. This gradually stopped going, no point in pushing it as she points blank does not want to go. She does not really want to go out the house anymore even refusing to take the dog a walk round the block.

Second year at school she has started to slip and is always late for school. Even if we get up early, she still manages to be late. She has no sense of urgency and does not seem to care if other people are then late. At primary school she would often take herself away and stand in the furthest end of the football pitch. Complaining of noise and people. It is all the sensory issues around the school.

Always needing to be preoccupied or would manage to cause a situation. Often not noticing the other people around us. Regularly start a fight with other family members, often causing injury. Has never been worried or has any empathy towards any of us. Now I have a sore shoulder and when she is off on one, she goes for my shoulder prodding it.

Always been taken everywhere. I have never been able to let her out to play. She always ran across the road without looking and still does it to this day. She has a mobile phone so I can contact her. She gets on school bus but needs a bus pass to get home. Her brother gets on the bus too so he can keep an eye on her. Not so long ago she did not arrive home from school. It was 17.30pm and she was not answering her phone. I went out in the car looking for her. She had got off the school bus with a friend to go into the shops. The friend lived there so she walked it home and her phone was dead. Sounds fine but I always need to know where she is because she can be very unpredictable. She does not seem to understand some danger. She is getting better but wanted to go a walk to the forest with her friend. When I asked her why she said to look at the reservoir. This is the same reservoir the school tell the kids not to go near as one of the pupils drowned in it.

Having trouble with personal care, been going on for a couple of years now. This is a trigger and will cause her to have a meltdown. Now she goes in for a shower once a week with a

fight. I am stumped with tried everything of which I can think. I do not understand it she liked the bath when she was younger. When she was escalating if I caught her soon enough, she would go in for a bath and that helped soothe her.

She causes a lot of upset in the house due to her behaviour. If she is in the mood to start things, she will annoy her brother by taking his things. This results in a fight which she seems to enjoy. Then she will start on me by repeating what she is saying over and over. If she does not get the reaction, she craves she will try to damage the house. The lights in the living room and the glass doors have a been a target lately.

When she comes in from school, I can usually tell what kind of day she has had. Before at primary I would open the front door, her bag would get thrown and she would have a meltdown. This has happened at high school, so I have been straight on the phone to get a team around the child meeting.

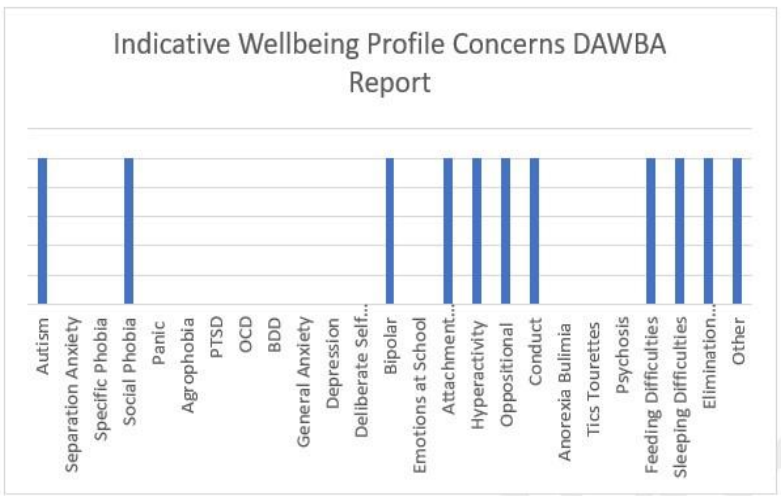
It is worth pointing out that she has an ADHD Diagnosis.

She is capable and has a lot of potential, but I know I need to keep an eye on her.

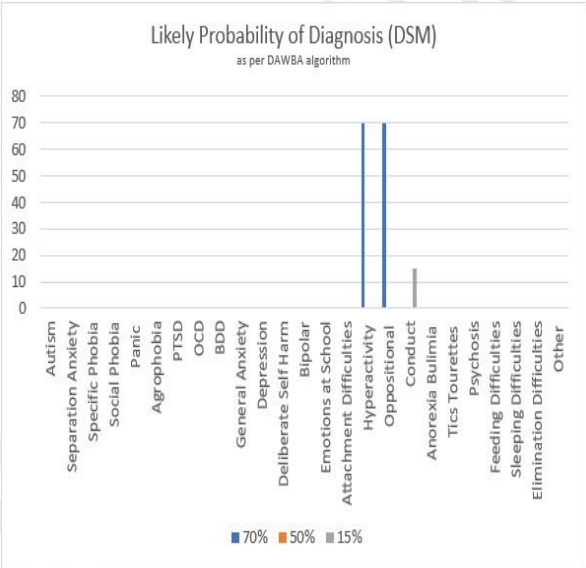
Development and Wellbeing Assessment Summary

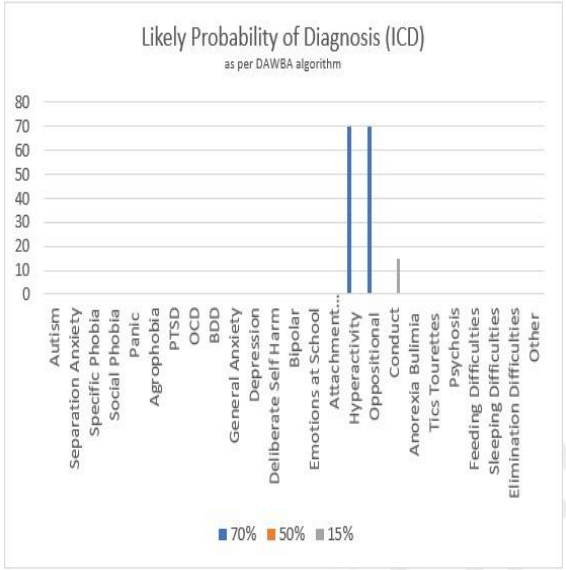
Considerations DAWBA -- ADHD combined, Oppositional defiant, Conduct disorder.

DAWBA profile suggestive of ADHD/ODD/CD comorbidity, hence difficulties in supporting challenging behaviours. Considerable home adjustments and problems noted. Bipolar over-ruled as no evidence of mania and episodes better explained at this stage by hyperactivity. ASD contribution unclear. Marked egocentricity may be explained by social immaturity and prolonged avoidance (hence lack of development) caused by perception of repeated "failure". Insufficiency of clear ASD diagnostic profile or collateral information from school. Certain rigidities in behaviour but RRS characteristics are vague. Language and communication issues worth exploring further to determine level of understanding and access to social skills. Similarly social motivation. Current functioning points towards potential future difficulties in sustaining engagement with education and overall mental health resilience. Uncertain impact of Covid lockdown arrangements on current functioning/presentation and stage in transition (P7-S1). Comprehensive school observation would assist formulation as would evaluation of cognitive function and presence of any organisational or specific learning difficulties. Current Dx of ADHD appears to be supported by DAWBA. Clinical involvement also noted. Sleep and elimination problems noted. Family under considerable strain. SUGGESTIONS: 1. Comprehensive school observation (including



unstructured periods), 2. Consideration of general learning profile including relative strengths and weaknesses, 3. Exploration of potential islands of competence as opportunities to build self-esteem and promote positive interactions with staff and peers, 4. Consideration of enhanced transition to HS and support that may be required to make this successful, 5. Social skills assessment, 6. Support with ADHD - helping her to understand own difficulties.





Advocacy Response

Having advocated for a substantial number of clients over the years, one realises advocating can be more than a single issue. It is about the person, the team, including family, the processing and system, with outcome beyond more than an output, beneficial for individual, family, and the practitioners and professionals collaborating with them, with an objective harmonising horizontal discussion.

The focus of considerations and suggestions below have taken account an overall common interest holistic advocacy approach for a positive collaborative partnership where all adopt and a co-produtcive participatory engagement resource in practice. In short Inclusive and Together.

This young person's DAWBA report is suggestive of an underlying 'disorder' with current functioning pointing towards potential future difficulties in sustaining engagement with education and overall mental health resilience.

One may consider advocating for further investigations as indicated within the DAWBA report as well as consideration for additional support via

a) Sharing the DAWBA with professionals that collaborate with this young person for potential follow-on assessment as
b) The suggestions within the DAWBA may bring to the fore additional understanding of oneself for oneself and further guide professionals and family into a more asset-

based approach building on strengths re social interaction and resilience re overall wellbeing optimising benefit of the individuals islands of strength.

c) Explore further how best to implement an education and wellbeing plan that is achievable and workable.

Feedback and actions taken

This individual and family and their supporters fed back that

- *project information and consent provided sufficient information, explained their rights and they had no requests for reasonable adjustments*
- *the online questionnaires were easy to follow and straight forward enough*
- *shared the report with CAMHS and aspects of it with the school*
- *believed the report would add value in determining actions and outcomes with both people and services they interface with*
- *the report and advocacy response will reduce the adversarial conversations re care, diagnosis and in place supports*

This YP now has a dual diagnosis of ASD ADHD, and the benefits of this pilot has

- *Contributed to actions on diagnosis*
- *Action on wellbeing supporting GIRFEC/ SHANARRI Indicators and much more.*
- *Added value to parent /professional partnership working*
- *Added value to school/staff support*
- *Supported parent/professional requests for access to*
  - *Nurture base*
  - *Let us Introduce Anxiety Management*
  - *Transitions course*

The outcome and action taken will be on the table at the next Team Around Child meeting along with a consideration request from parent for either a base placement or to hybrid model.

Consent, through assessment to actions including diagnosis - 92 days

"Thank you for enabling us to be part of this triage pilot project. Long awaited, much needed"

Case Study Sample F

Summary Profile Pilot *Categorisation —Education*

This is young male adult resident in Central Scotland, in high school and experiencing challenges and difficulties in his daily life.

Participant Overview (own words)

He cannot go a full day or usually a full hour without being agitated with parents or siblings. He would never misbehave in school and is described as well-mannered and respectful there in stark contrast to home.

He is also rude to health staff, hospitality staff and previously to grandparents/aunts (but no longer to relatives as they avoid any demands whist in their care). He explains this that we all annoy him and hates that we tell him what to do. Parenting styles have been majorly adjusted to meet his needs and things that are expected from his siblings are not expected from him as aware he seems unable to meet the demand.

He dislikes praise and unlike other children that it would motivate them to repeat the behaviour it often has the opposite effect and angers him, as a young child he would never except stickers even from dentist, doctors etc. He had an extreme stammer that came on suddenly aged 2 years 4 months and lasted until aged 4 years.

As a child he was frequently unwell until aged eight when he seemed to grow out of it. He had a constant cold and frequent ear infections, tonsillitis and even when got chicken pox it was more severe than any other child.

He was an incredibly happy baby and met all his developmental milestones, his speech was exceptionally good, and he spoke at an early age like his siblings, the only difference was he did not often speak in front of others and would present as shy. The first couple of years of primary he would present as quite quiet in class and in p1 did not speak to the art teacher all year.

Our son has always been sensitive to certain noise or smells and from aged one would be extremely distressed by fireworks. He would complain about the smells of other people's houses and would say this loudly in front of them. He is extremely sensitive and irritable about clothing; he prefers dry fit clothes. He also prefers clothes when they are brand new and not been washed before once washed he will blame me that I have ruined them and they feel different and then usually refuse to wear them .In primary he would not wear school trousers he would be verbally and physically aggressive when attempts were made for him to wear them so joggers were purchased instead. He describes certain fabrics feel like needles on his body and when trying on you can often see the discomfort. Clothing often leads to arguments especially at times when certain clothing is to be expected like when attending more formal occasions. He would happily live in shorts and t-shirt but only if dry fit material.

Despite his dislike of noises, he is very loud and loves to play his music very loud. He gets terribly angry if his sister cries and will shout and be nasty to her about this despite it being appropriate for her age.

He would be able to show empathy to a friend that was sick but not a member of the family. When I was unwell with covid he was incredibly angry with me and blamed me for having to isolate despite us previously isolating due to him, he said that was different as it was not his fault.

Despite me being on the go constantly and rarely sitting down he feels I am lazy; he gets angry if children appear "lazy" to him if they do not play out for hours the way he wants too. He has a good sense of humour and understands jokes, sarcasm, facial expressions, change of tone and other changes in body language and he is also able to demonstrate these and clearly shows a change of emotions.

Day trips and holidays can be extremely difficult with him, and our last trip abroad 3 years ago was exceedingly difficult he spent the full week been verbally and physically aggressive to us all. Often, he feels things do not meet the expectation of what he thought they would be like. He will comment it was waste of money even though we have paid for it.

He hates me for sending him to school and even though school feel like he enjoys it he tells me he hates it and wants the teachers all to die. He often uses strong language like this and will say wants to kill his brother and wishes he were dead; he also will say to me to go kill myself and die. This can simply be for waking him for school. He never wakes up nicely he will shout and scream at me despite lots of adjustments made to help him like not putting on the lights giving him longer to come round unlike siblings. He will also say he wants to kill himself and this will be for just getting asked to do something usually a simple request like tidy up etc. He will expand on it and say things like I will get a knife and stab myself. He says he feels people look at him and likes to wear a cap as it makes him feel more comfortable as people cannot fully see him.

His perception is not actually true of the event, for instance if a parent must physically get him to his room due to behaviour and safety for siblings etc he will shout and scream that he is being abused. He will do these other times if even bumped into. He often does not remember his behaviour and will say i did not say or do that and he really does not remember or remembers it differently. He does not like to say sorry and if he does will always say "but "afterwards and say it our fault. Or like if he has punched me, he will say you are lucky I did not punch you in the face as I wanted too.

He is hypermobile and OT have said his fingers are very hypermobile making writing painful and more difficult. His older sibling would describe him as a "bully," and he goes out his way to be unkind to him despite his sibling being kind and easy going.

He directs his anger towards me, but Dad works long shifts and is not home a few evenings but when he is off on holiday etc. or weekend off, he will display similar behaviours to him although has never punched him but will clench his fist to do so but has pushed him before and destroyed property. He says he likes Dad more than me yet will be me that he comes to

when wants to ask anything or problems, issues and would be me he wants to tuck him in at night or he will text to tell me something. He had extreme separation anxiety with me from a baby to 8/9 years. During this time, he would be really upset when left at school or with other family members although not with Dad. He would never seek support from another adult if upset and tells me he would only speak to me about a problem.

He finds it extremely difficult to fall asleep and this is even worse on holiday, and he will shout and annoy others due to this. This is true also if we stay in hotels, his behaviour will be incredibly challenging aggressive to his oldest sibling.

Completed by parents and with some contribution of information shared with the individual himself.

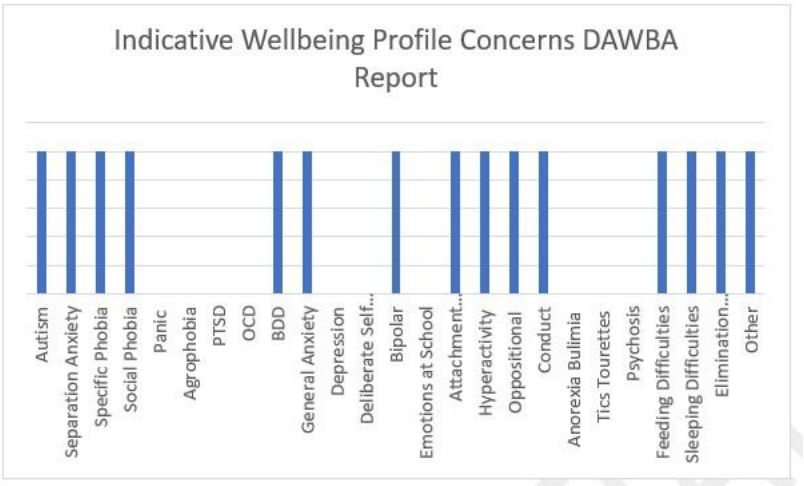
Development and Wellbeing Assessment Summary

DSM-IV diagnoses. ADHD combined. Specific phobia?? Oppositional defiant

NB differential parental impact scores which require further explanation. Sufficient indication of sensory difficulties to warrant OT assessment and anxiety/phobic responses to require further exploration. Marked egocentricity suggestive of ASD-type profile but insufficient RRS behaviours to indicate this as meeting diagnostic criteria.

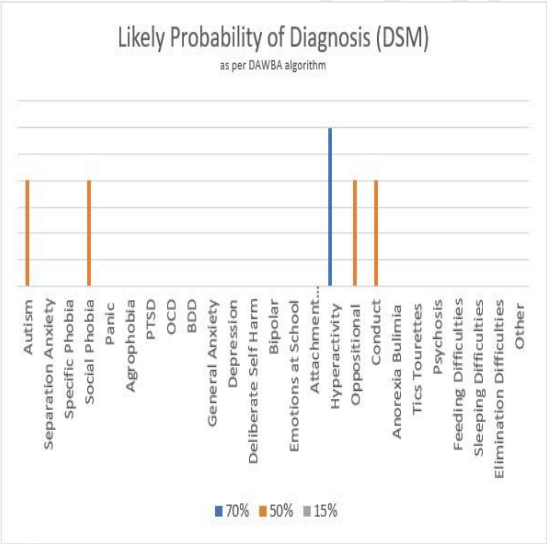
However, empathy deficits noted as significant. PDD/NoS? Social and communication dysfunction may be associated with immaturity re understanding and accessing skills (also NB social motivation) rather than absence of such capacity.

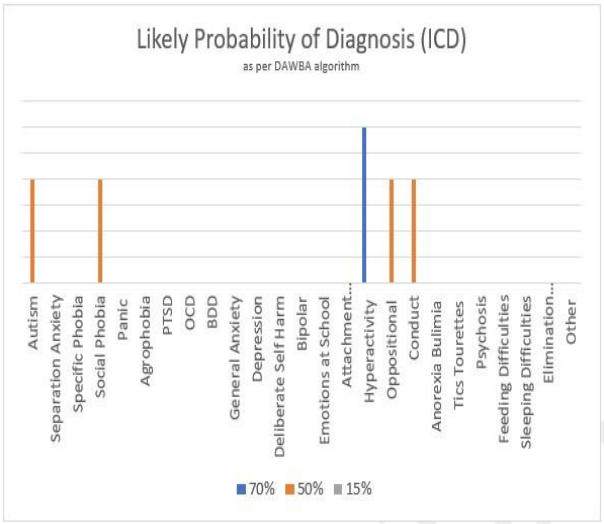
Demand avoidance very evident from responses and identifiable as a trigger for challenging behaviours. QoL likely to be improved by understanding and supporting underlying anxieties. Treatment options could be explored. Low self-esteem. NB contribution of sleep disruption to mood, behaviour, and daily function. Self-report provides interesting contrast to parental scores and may be indicative of problems in understanding relationship between self and others, and an illusory bias re current function.



SUGGESTIONS: 1) Further exploration of possible NDD contribution to current difficulties inc. differential Dx, 2) Assessment of social understanding and current capacity to access social skills, 3) Collaborative work with parents to explore behaviour management strategies in order to ensure consistency and provide positive reinforcement, 4) OT assessment re

sensory difficulties and anxieties and possibility of a sensory plan based on elimination of triggers and enhancement of sensory diet.





Advocacy Response

This person's DAWBA report is indicating a range potential concerns which warrant further considerations which may be helpful in service targeting with tailored interventions supportive of the individual family and professionals who collaborate with him after formal identifications.

In this case, based on the DAWBA report and the PO, we would suggest advocating sharing of the report, considerations and development of effective actions going forward.

In appreciating the challenges, we would suggest strong advocating support for a plan that incorporates the considerations within his DAWBA. It is, however, more the content of a good plan that is significant rather than the type of plan.

There are many ingredients and inclusions in making a good plan.

In consideration of a good actions, one may include some or all the following and more depending on further assessment:

- Outcome focussed to benefit the individual, make targets achievable and measurable
- Undertaking of further assessment and identification
- Ensure holistic education and social development both in and out of school
- Encompass the individual as far as capacity enables in the development of their plan to the best of their own capability (provide supportive advocacy if required) (use supportive communication tools if appropriate). This ensures CYP's rights to inclusion and participation are being met.

- Take account of environmental / sensory issues often a key trigger, a trigger and solution analysis may be helpful. If undertaking would suggest this is done both in and out of school and in and out of classroom.
- Have an initiative-taking partnership approach which includes individual, parent/carers, practitioners
- Be inter-agency connected, health, social care, including third sector clubs etc. if and as appropriate.

Given this young person, may qualify for access to independent advocacy under https://www.partnersinadvocacy.org.uk/advocacy-for-children-and-young-people/ or check the SIAA website https://www.siaa.org.uk/find-an-advocate/

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Feedback and Actions Taken.

"We found the questions in the questionnaire to be relevant and it also allowed at times to expand and give a more detailed description of some of the behaviours."

"An APP version would for some be easier to use"

"Language adapted more to suit children to help make completing it easier for them."

"We do feel like services will clearly see the areas we and our son need most support with."

"Our son himself felt that there were not enough questions related to sensory issues, we were able to add lots of our own information in about this but felt more direct questions around this were lacking."

"We found the report fully accurate, and it validated a lot of the thoughts we have around our son's difficulties. This was a positive experience for us, as over the years we have struggled to find services that understand fully the issues we face and were insistent that due to not having faced significant trauma our son could not have certain conditions that we ourselves had researched and felt likely."

Table re Suggestion for Consideration and Self-directed Partnership Identified areas of action

Target / Tailored Provision	**Cross all Applicable**
Comprehensive School Observation	
Identify General Learning Profile/Plan	
Identify Strengths and Weaknesses	**x**
Potential Islands of Competence	
Promote Self Esteem / Reinforcement of success	**x**
Promote Positive Interactions	**x**
Enhanced Transitions	
Social Skills Assessment	
Support Self Awareness	**x**
Masked Disorder or Masking weaknesses	
Adult Screening for Additional or Differential Assessment re DX	
Screening for Additional or Differential Assessment re DX	
Social Competence Functions /Language SPLD/Comms Passport	
Cognitive Functioning /Profiling/ Match to Attainment	
Sensory Assessment and Profile	**x**
School Adjustments re Anxiety / Demand Led Challenges	**x**
Academic Adaptations re Curriculum	
Explore Open Text Answers	
Comprehensive Development Disorder Factors	
Emotional and Development Factors	**x**
Executive Function Deficits	
Determine Risks (Self Harm/Substance/Sexual)	
Eating Difficulties	
CBT potential Benefits re Anxiety/OCD	
Increase Social Inclusion (Support) and QOL v Attainment Goals	
AHP Assessments SLT % or OT	
Social/Friendship Inclusion and Development	
Clarification of Age/Stage expectations/supports	**x**
Psychological Interventions re PTSD	
Family supports	**x**
School Staff Supports	**x**
Individual feeling safe (inclusive of social fears)	
Recent bereavements noted and support options explored	
Workplace Adjustments	
Voice being Heard / need for trusted adult	**x**
Post School Planning	
Reasonable Adjustment in Employment	
Improved Individualised Employment Placement	
Disabled Student Support Application	
Other	

"The report has been shared with school who feel it has helped them understand our son's needs more and put strategies in place to support him. I have contacted O.T who plan to come in to school to assess him further and I have an appointment with them to discuss the report. We feel we will continue to use this in the future if we require any other services to meet his needs."

"We feel it gives us a stronger voice when speaking to services and also reduces the need to repeat the difficulties we face whilst being able to easily facilitate discussion."

"It has enabled improved more balance discussion between professional to professional and us. Improved inclusion in planning and supported co-productive decision making."

In this instance this report was issued a few days before transitioning planning meeting and the feedback from this clearly indicates when parents staff and professionals are working with partnership approach actions can happen. Especially when based on an informative effective holistic overview, having an eye on the suggested areas of action for this young person.

We can as a collective team envisage actions if implemented having positive impact of delivery within the following policy areas –

- *Getting it Right for Every Child,* [7]
- *The Promise* [23]
- *The Accountability Gap* [24]
- *All Our Children All Their Potential* [5]
- *The Additional Support for Learning Action Plan (ASLIP)* [25]
- *The Neurodevelopmental Specification: Principles and Standards of Care* [29]
- *United Nations Convention on the Rights of the Child* [7]
- *The Equality Act* [30] *and UNCRPD* [31]
- *The National Mental* Health *Strategy 2017-2027* [32]
- *The COVID Recovery Strategy – A Fairer Future* [33]

and more

Case Study Sample G

Summary Profile Pilot *Categorisation —Education*

This is young male resident in Central Scotland, transitioning from primary to secondary school, with a number of challenges that are impacting on his daily life, with wait after waiting for assessments.

Participant Overview (own words)

Often concerned with social relationships, particularly in school where interactions are tense. This because I feel anxious about interacting with people, I find difficult to have a good relationship with, where I feel their treatment of me goes unrecognised. I find making friends difficult. I feel like I am not liked by most of the people in my class and I feel harassed.

I worry about going to school most of the time because I am afraid of having a difficult day. I feel some teachers favour some students to a degree where they get away with treating me unkindly. I feel most of the teachers at school do not listen to me regarding conflict. I often feel frustrated and angry when something does not go well for me. This can include schoolwork where we are required to work in groups.

I prefer clear rules and guidelines and I do not like it when others do not follow these rules. It seems pointless to have rules if everyone does not have to follow them.

I like playing on-line but avoid playing if there is more than one other person in a game. I do not like playing with groups of people. I also do not like team sports because I do not feel valued, like others think I am rubbish.

I often feel lonely, sometimes life feels pointless because I feel isolated. I do not sleep well. I struggle to get sleep; I often wake in the night and then cannot get back to sleep. I feel tired all the time. I feel sad a lot and I do not know why.

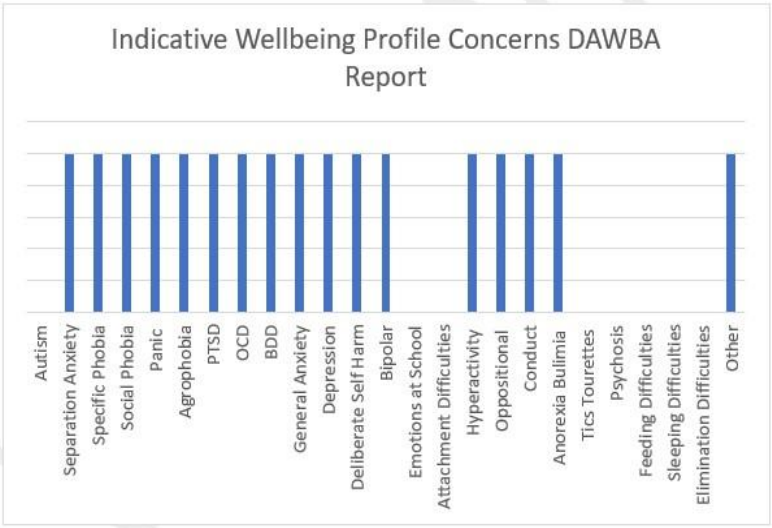
My son is very articulate and can express his concerns well, but he has suffered from exceptionally low moods and his comments are sometimes worrying. He has always been a poor sleeper, and this is a major factor in how he feels. He can take a couple of hours to get to sleep or he can wake in the night and be up for a few hours before going back to sleep. The social isolation and lack of routine through lockdown has had a detrimental effect on his happiness. As a family, we were not concerned about him before lockdown. He has always seemed a little “different,” but there were no red flags. He recognised Autism in himself before anyone else, he identifies with some autistic traits.

Development and Wellbeing Assessment Summary

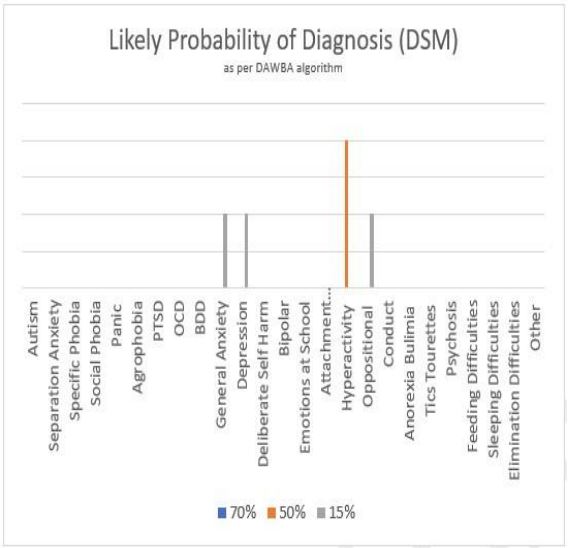
Asperger ??ADHD inattentive

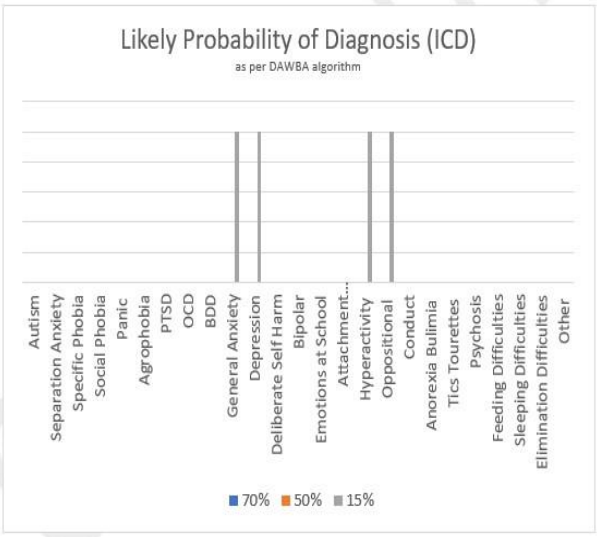
NOTE TRANSITION NEEDS OF THIS YP. Profile of a young person with subtle but significant difficulties in social interaction and development which are having a considerable impact on his sense of self and emotional well-being. Causation is problematic given information

available but there is evidence of certain rigidities in thinking and behaviour and a marked egocentricity that cause barriers both at home and at school, and in social situations. Notable is the quality of information provided in his self-report and the higher level of impairment that he himself identifies. Both ASD and ADHD (inattentive presentation) are viable as potential diagnoses but require further assessment, as does his capacity to understand and communicate with his peers. Assessment would benefit from school input and a detailed school observation. Given self-identified needs, any future intervention is likely to focus on his social development, sense of being included, and opportunities to interact with like-minded peers. Recommendations would include a strengths-based approach to support and the enhancement of opportunities to explore areas of relative strength and interest (e.g., expressive, and creative arts).



SUGGESTIONS: one. Detailed school observation (NB 'masking'), 2. SALT assessment (receptive and expressive language skills and social understanding), 3. Assessment for both ADHD (inattentive) and ASD, 4. Provision of opportunities for interaction in small groups, 5. Differentiated curriculum to allow opportunities to develop islands of competence, 6. Positive reinforcement of current strengths to improve wellbeing.





Advocacy Response

This young person DAWBA report questions ASD/ADHD inattentive, with subtle yet

significant difficulties in social interaction, development, and sense of self and his emotional wellbeing. Highlighting the current overarching challenges that he, his family, practitioners, and professionals working with him are facing.

In this case, based on the DAWBA report and the PO, we would suggest advocating sharing of the report, an effective positive transition plan with considerations of some key questions outlined in table below.

Key Question	Yes	No
Is the family doing all they know how to or with advice and guidance attempting to do the right thing re his assessments and interventions		
Does he have complex or multiple needs which have a significant adverse effect on his learning?		
Does the he have Additional Support Needs?		
Will his Additional Support Needs last for more than a year and perhaps be longer without early support building assets, understating and resilience		
Does his Additional Support Needs require a significantly high level of co-ordinated input to educational planning from one or more agencies in addition to Education?		
Is there and what is the need re substantial and/or significant additional support provided by Education re Continuum of Support model?		
Does he have a detailed Child's Plan? More specifically in this instance a 'Transition Plan' to support a Child Plan		
Is the Education Authority responsible for the education of the child or young person?		
Would he, his parents and front line educators and support staff benefit from input from allied health specialists associated to his needs?		
Is there a need for potential further exploratory assessment by appropriate specialists?		
Would he benefit in the short, medium or longer term, from one of the following – Child's Plan, Coordinated Service Plan, Staged Intervention Plan, Individualised Educational Programme, Personal Learning Plan ? https://education.gov.scot/parentzone/additional-support/how-schools-plan-support/types-of-plan/#:~:text=Co%2Dordinated%20Support%20Plans,-This%20statutory%20plan&text=Your%20child%20may%20be%20eligible,non%2Deducation%20service%20or%20agency		
Would both advocacy support and further parental support be beneficial for him and his family?		

As he self identifies with some autistic traits it may be worth accessing My Autism Profile https://www.southlanarkshire.gov.uk/downloads/file/13763/my_autism_profile

In appreciating the challenges, he is currently facing, we would suggest strong advocating support for a plan that incorporates an implementable approach to transition. It is, however, more the content of a good plan that is significant rather than the type of plan.

There are many ingredients and inclusions in making a good plan.
https://www.autismnetworkscotland.org.uk/documents/view/c356b7c5-143a-48b5-92c9-df2e09e1b146

In consideration of a good plan, this may include some or all the following and more depending on further assessment:

- Outcome focussed to benefit the individual, make targets achievable and measurable
- Undertaking of further assessment and identification
- Ensure holistic education and social development both in and out of school
- Encompass the individual as far as capacity enables in the development of their plan to the best of their own capability (provide supportive advocacy if required) (use supportive communication tools if appropriate). This ensures the CYP's rights to inclusion and participation are being met.
- Take account of environmental / sensory issues often a key trigger, a trigger and solution analysis may be helpful. If undertaking would suggest this is done both in and out of school and in and out of classroom.
- Have an initiative-taking partnership approach which includes individual, parent/carers, practitioners
- Be inter-agency connected, health, social care, including third sector clubs etc. if appropriate
- Additional consideration may involve 'flexi start/end' of school day and 'flexibility' in subject change, some schools have adapted to this for some pupils very successfully.

It may also be worth two further considerations for exploration (eligibility criteria may apply) to help support him and his confidence and resilience building.

Access LIAM sessions – LIAM – Lets Introduce Anxiety Management.

PLUS, Forth Valley offer support groups clubs that may be beneficial. They used to, do not know if they still do, have one specifically for autism. http://plusforthvalley.org.uk/

Central Advocacy Partners have a project Autistic are Awesome
http://centraladvocacypartners.org.uk/projects/youngautism.aspx

Finally, he is within the age category for Independent Advocacy My Rights My Say
https://myrightsmysay.scot/

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Feedback and Actions Taken.

"We found the report very thorough.

Table re Suggestion for Consideration and Self-directed Partnership Identified areas of action

Target / Tailored Provision	**Cross all Applicable**
Comprehensive School Observation	
Identify General Learning Profile/Plan	
Identify Strengths and Weaknesses	**x**
Potential Islands of Competence	
Promote Self Esteem / Reinforcement of success	**x**
Promote Positive Interactions	**x**
Enhanced Transitions	
Social Skills Assessment	
Support Self Awareness	**x**
Masked Disorder or Masking weaknesses	
Adult Screening for Additional or Differential Assessment re DX	
Screening for Additional or Differential Assessment re DX	
Social Competence Functions /Language SPLD/Comms Passport	
Cognitive Functioning /Profiling/ Match to Attainment	
Sensory Assessment and Profile	**x**
School Adjustments re Anxiety / Demand Led Challenges	**x**
Academic Adaptations re Curriculum	
Explore Open Text Answers	
Comprehensive Development Disorder Factors	
Emotional and Development Factors	**x**
Executive Function Deficits	
Determine Risks (Self Harm/Substance/Sexual)	
Eating Difficulties	
CBT potential Benefits re Anxiety/OCD	
Increase Social Inclusion (Support) and QOL v Attainment Goals	
AHP Assessments SLT % or OT	
Social/Friendship Inclusion and Development	
Clarification of Age/Stage expectations/supports	**x**
Psychological Interventions re PTSD	
Family supports	**x**
School Staff Supports	**x**
Individual feeling safe (inclusive of social fears)	
Recent bereavements noted and support options explored	
Workplace Adjustments	
Voice being Heard / need for trusted adult	**x**
Post School Planning	
Reasonable Adjustment in Employment	
Improved Individualised Employment Placement	
Disabled Student Support Application	
Other	

"We have shared the report with school, and it will be shared also with CAMHS."

"An option to say 'this doesn't apply to me' for some questions would be extremely helpful. Supporting processing especially for children and young people."

"Sometimes responses like 'never' 'occasionally' or 'always' can be hard to choose. Just felt there was a need for further explanation."

"As my son is transitioning from primary to secondary school, we consented to the report being issued direct to my son's primary school with the advocacy response to his secondary school. We were delighted with the reception and action from his secondary school."

"It is hard to know how CAMHS will receive and interpret the report, as many practitioners are set in their ways."

"As parents the report was very informative and helped us understand and identify the issues affecting our child."

"From previous discussions, Action when and if implemented could have positive impact on and delivery within a broad range of policy and practice areas."

"The transition lead with the secondary school acted promptly with a same day response to the pilot team asking what she could be doing in the meantime."

"The pilot team responded professionally suggesting the importance of discussion within my sons transition planning meeting"

"We will be using the report and soft advocacy response to enhance my child's assessments, and actions for improved outcomes."

"I would like thank Autism Network Scotland for nomination referral to this pilot."

<u>As well as having positive and important impact on my son.</u>

Case Study Sample H

Summary Profile Pilot *Categorisation —Education*

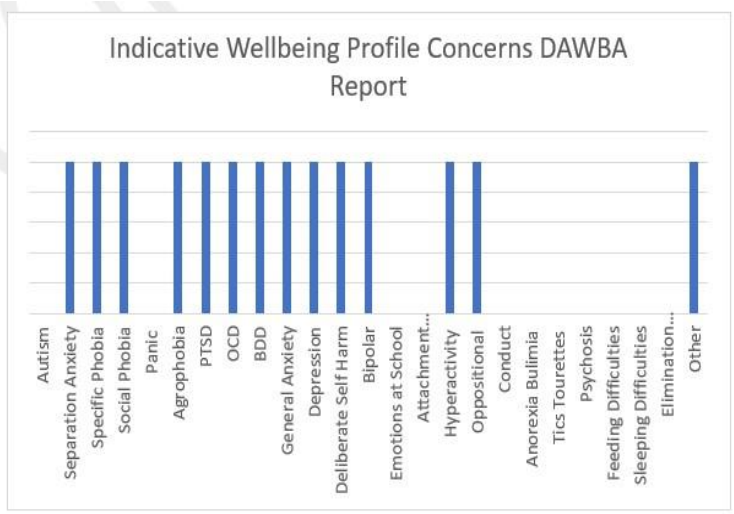
This is young male resident in Central Scotland, part way through high school and experiencing challenges and difficulties in his daily life.

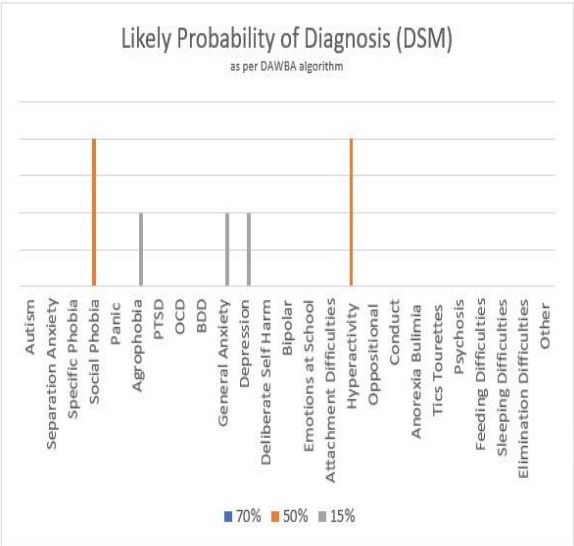
Participant Overview (own words)

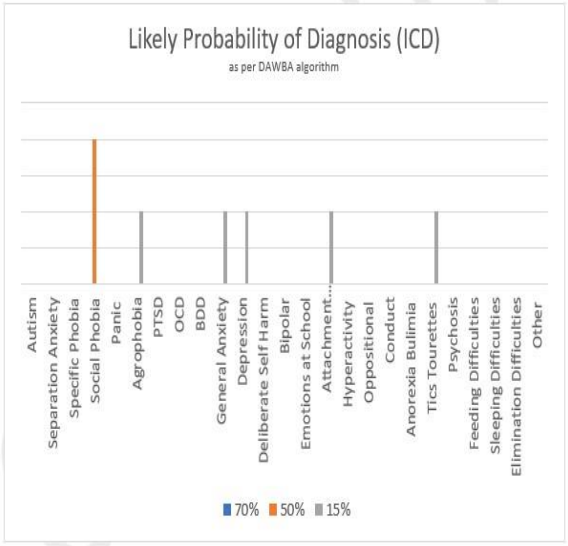
I was always aware of adaptions I would need to make for my middle child's environment from when he was around 8 months old, we lived with clear boundaries and a structured routine which enabled my other two children to manage well. In both my other two children's development I have become aware of them both struggling with managing school life, maintaining relationships especially healthy ones for my oldest daughter and anxiety. This has been more apparent as they reach adolescence where they are freer in their own daily life and more challenges of different routines in high school.

Development and Wellbeing Assessment Summary

High and consistent impact scores. Evident low self-worth and difficulties in establishing and sustaining friendships. Experiencing problems with P7-S1 transition. NB impact of covid restrictions on continuity both of education and social development. ADHD rated. Some repetitive behaviours (not OCD) but insufficient information to suggest ASD as contribution. Worth exploring executive function capacity and emotional maturity. Social disconnect with peers due to immaturity/lack of confidence rather than absence of skill. Sufficient sensory difficulties to warrant further analysis and intervention (e.g., sensory diet). Family stress also noted as contributory factor. SUGGESTIONS: 1. ADHD assessment, 2. ASD screening given family 'risk', 3. OT assessment, 4. Support at school re friendships groups with potential adjustments to curriculum, 5. Emphasis on strengths-based learning and exploiting relative strengths, 6. Support to enhance self-esteem and build resilience.







Advocacy Response

This young person's DAWBA report is indicated a range potential concerns which warrant further considerations which may be helpful in service targeting with tailored interventions supportive of the individual family and professionals who work with this individual.

In this case, based on the DAWBA report and the PO, we would suggest advocating sharing of the report, considerations, and development of an effective support positive support plan with considerations to include some key questions for example, see table opposite.

In appreciating the challenges, we would suggest strong advocating support for a plan that incorporates the considerations within his DAWBA. It is, however, more the content of a good plan that is significant rather than the type of plan.

There are many ingredients and inclusions in making a good plan.

Question for consideration by self and his parents and partnering professionals	Yes	No
Is the family doing all they know how to, with advice and guidance attempting to do the right thing re individual assessments and interventions		
Would he benefit by further exploratory assessment by appropriate specialists?		
Would he and his parents and front line educators and support staff benefit from input from allied health specialists associated to his's needs?		
Would he and his family benefit from identified social care or third sector supports?		
Does he have complex or multiple needs which have a significant adverse effect on his learning?		
Does he have Additional Support Needs?		
Will the Additional Support Needs of this person last for more than a year and perhaps be longer without early support building assets, understating and resilience?		
Do his Additional Support Needs if identified require a significantly high level of co-ordinated input to educational planning from one or more agencies in addition to Education?		
Is there and what is the need re substantial and/or significant additional support provided by Education re Continuum of Support model?		
Does he have a detailed Child's Plan supporting both education and wellbeing indicators?		
Is the Education Authority responsible for the education of him?		
Would he benefit in the short, medium or longer term, from one of the following – Child's Plan, Coordinated Service Plan, Staged Intervention Plan, Individualised Educational Programme, Personal Learning Plan ? https://education.gov.scot/parentzone/additional-support/how-schools-plan-support/types-of-plan/#:~:text=Co%2Dordinated%20Support%20Plans,-This%20statutory%20plan&text=Your%20child%20may%20be%20eligible,non%2Deducation%20service%20or%20agency		
Would both advocacy support and further parental support be beneficial for this person and his family?		

In consideration of a good plan for this young person, this may include some or all the following and more depending on further assessment:

- Outcome focussed to benefit the individual, make targets achievable and measurable
- Undertaking of further assessment and identification
- Ensure holistic education and social development both in and out of school
- Encompass the individual as far as capacity enables in the development of their plan to the best of their own capability (provide supportive advocacy if required) (use supportive communication tools if appropriate). This ensures the CYP's rights to inclusion and participation are being met.
- Take account of environmental / sensory issues often a key trigger, a trigger and solution analysis may be helpful. If undertaking would suggest this is done both in and out of school and in and out of classroom.
- Have an initiative-taking partnership approach which includes individual, parent/carers, practitioners
- Be inter-agency connected, health, social care, including third sector clubs etc. if and as appropriate.

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Feedback and Actions Taken.

"The questionnaire took me far longer than I had anticipated, this was more because of trying to get others to engage in the process. The questions covered more insightful direct questions that I have previously experienced, which, for me, indicates a well thought out process which will highlight and identify a more precise evaluation of individual's needs. "

"I think moving forward that if someone is completing this questionnaire that they should task themselves with completing small sections at a time and not all at once, I also believe that moving forward, if someone can be appointed a role that they assist individuals to complete the questionnaire wither in person, call or video link if they feel they need this assistance. The questions are relevant and unsure that if any removed would be of any benefit to the outcome."

"There was nothing I felt was missing, where I felt that the choices were not relevant there was space to explain why, this is something that I feel has lacked in previous family assessments and had been left feeling the questions were not a good all-round indicator of the person."

"Yes, we completed this as a family. I have three children who filled out a limited number of questions, which limits the information being received. This report was accurate, my middle son is autistic and ADHD and this didn't have a high percentage in his report, however, having had a conversation with pilot team about my sons mental health it was evident which had a high percentage indicator it was evident that this was extremely accurate as his mental health has been far more of a struggle for him in the past two years. Overall, I considered this report perfectly accurate and reflective."

"Yes, I have already shared this report of my child to the CAHMS crisis team, I also plan to share this with his support teacher to ensure he receives more support in school."

Table re Suggestion for Consideration and Self-directed Partnership Identified areas of action

Target / Tailored Provision	**Cross all Applicable**
Comprehensive School Observation	**x**
Identify General Learning Profile/Plan	**x**
Identify Strengths and Weaknesses	**x**
Potential Islands of Competence	
Promote Self Esteem / Reinforcement of success	**x**
Promote Positive Interactions	**x**
Enhanced Transitions	**x**
Social Skills Assessment	
Support Self Awareness	**x**
Masked Disorder or Masking weaknesses	
Adult Screening for Additional or Differential Assessment re DX	
Screening for Additional or Differential Assessment re DX	
Social Competence Functions /Language SPLD/Comms Passport	
Cognitive Functioning /Profiling/ Match to Attainment	
Sensory Assessment and Profile	**x**
School Adjustments re Anxiety / Demand Led Challenges	**x**
Academic Adaptations re Curriculum	**x**
Explore Open Text Answers	
Comprehensive Development Disorder Factors	
Emotional and Development Factors	**x**
Executive Function Deficits	**x**
Determine Risks (Self Harm/Substance/Sexual)	**x**
Eating Difficulties	**x**
CBT potential Benefits re Anxiety/OCD	**x**
Increase Social Inclusion (Support) and QOL v Attainment Goals	
AHP Assessments SLT % or OT	
Social/Friendship Inclusion and Development	
Clarification of Age/Stage expectations/supports	
Psychological Interventions re PTSD	
Family supports	**x**
School Staff Supports	
Individual feeling safe (inclusive of social fears)	
Recent bereavements noted and support options explored	
Workplace Adjustments	
Voice being Heard / need for trusted adult	**x**
Post School Planning	
Reasonable Adjustment in Employment	
Improved Individualised Employment Placement	
Disabled Student Support Application	
Other	

"I will use the report for all of my children especially where I feel my children and myself are not being heard, the indicators from the report are far too prominent to be ignored, and also to aid in the process of receiving the correct support."

"It has enabled improved more balance discussion between professional to professional and us. Improved inclusion in planning and supported co-productive decision making."

"It is worth noting, as a parent I believe all three of my children who took part in this pilot received very accurate and reflective reports."

"I have already had a positive response to this report from the CAMHS Crisis Team. I am in hope that moving forward it prevents us being sent to several different organisations and specialists and limits both the time this takes and the distress it causes with my children when they have had to repeat the same issues to many different people."

"I feel the report gives me a safe platform to communicate my concerns and also empowers my children to feel listened to by believing their needs are valid, past experiences have not always been positive and often minimised or dismissed."

"I can't thank the pilot team enough for all of their time, patience & knowledgeable advice"

Reflective Learning

Reflecting on the extract below from Judy Eaton's book about females and mental health and autism.

"Many parent carers report their biggest challenges post-diagnosis as being 'loneliness and isolation'…. It appeared most had given up hope of receiving targeted and timely support from professionals…This does raise a profoundly serious question about the usefulness of a diagnosis if that is all that is available…… the more likely they will be to develop mental health problems as they grow up, presenting even greater potential cost to society in the future…" [34]

That extract is a succinct summary of what we hear time after time, year after year, with report and reviews for decades informing us 'early intervention is both key and critical to prevention.

The Microsegmentation Report March 2018, [14] which informs us that in Scotland the annual cost of autism, £2.2bn and states that 42%, or if you prefer £924m, is escapable costs. Currently actions since and interventions, supports and opportunities are still to be measured to identify individual, service, and societal impact, if any?

The key pilot team are very aware, like many families, including their children and young people and partner professionals, statutory provisions often operate in silos as opposed to in parallel with a timely connected, cohesive approach, often overly dependent on singular committed individuals. Children and young people's wellbeing can have a significant impact of their abilities, not only educationally, but on all aspects of their daily living. A question we have heard throughout the study is "What has changed?" The reality, is yet, truly little. **But that does not mean it cannot**.

In our introduction we drew you towards our big questions as well as a range of smaller yet no less important subsidiary considerations.

We sought to, by suggesting that individual participants, their families, their supporting practitioners, and professionals, adopt a parallel partnership approach to coproductive actions.

It became clear by their actions and application of some of the commitments made from The Promise [23] to broader practice, in practice, for example

"Scotland must fulfil its commitments to early intervention and prevention"

"...children and adults must not require a significant mental health diagnosis before they can access support."

"Access to timely. Appropriate therapies must be available, not limited to those who have experience of care"

We recorded the number of times the same suggestion came up in a DAWBA report and subsequently recorded where we had been informed of actions. See table below.

DAWBA Suggestions for Consideration		
Comprehensive School Observation	**17**	**14**
Identify General Learning Profile/Plan	**7**	**6**
Identify Strengths and Weaknesses	**7**	**6**
Potential Islands of Competence	**6**	**4**
Promote Self Esteem / Reinforcement of success	**9**	**7**
Promote Positive Interactions	**6**	**5**
Enhanced Transitions	**1**	**1**
Social Skills Assessment	**5**	**4**
Support Self Awareness	**1**	**1**
Masked Disorder or Masking weaknesses	**3**	**2**
Adult Screening for Additional or Differential Assessment re DX	**3**	**2**
Screening for Additional or Differential Assessment re DX	**21**	**16**
Social Competence Functions /Language SPLD/Comms Passport	**14**	**9**
Cognitive Functioning /Profiling/ Match to Attainment	**11**	**8**
Sensory Assessment and Profile	**4**	**3**
School Adjustments re Anxiety / Demand Led Challenges	**6**	**4**
Academic Adapations re Curriculum	**3**	**2**
Explore Open Text Answers	**1**	**1**
Comprehensive Development Disorder Factors	**1**	
Emotional and Development Factors	**1**	**1**
Executive Function Deficits	**3**	**2**
Determine Risks (Self Harm/Substance/Sexual)	**4**	**3**
Eating Difficulties	**2**	
CBT potential Benefits re ASD adaptation where appropriate	**3**	**2**
Increase Social Inclusion (Support) and QOL v Attainment Goals	**5**	**4**
AHP Assessments SLT % or OT	**11**	**8**
Social/Friendship Inclusion/Development +Activities	**4**	**3**
Clarification of Age/Stage expectations/supports	**3**	**2**
Psychological Interventions re PTSD	**1**	
Family supports and dynamics	**4**	**3**
School Staff Supports	**1**	**3**
Individual feeling safe (inclusive of social fears)	**3**	**2**
Recent bereavements noted and support options explored	**1**	
Workplace Adjustments	**1**	
Voice being Heard / need for trusted adult	**2**	**2**
Post school planning	**6**	**5**
Advocacy Input	**25**	**2-20**

Outcome and Learning Point: In its simplest of term, by adopting a multi-disciplinary approach in parallel, this equates to an astonishing **74.87%** self-directed in partnership areas of identifiable action. Not surprising is the diagnostic numbers, twenty-one identified but only nine actioned.

How did those actions come about?

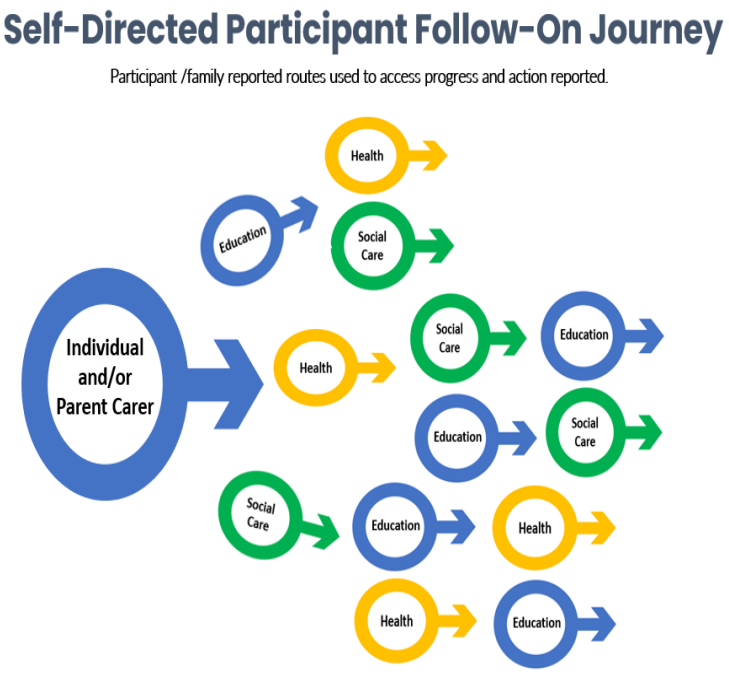
The fact that the DAWBA report is a co-created document means the dissemination of this report remained entirely self-directed. Having the completed and rated report in the possession of the assessed individual and their parent/carers/legal guardian resulted in varied responses from professionals in different agencies, which appeared to be influenced by the route recipients took, via education, health, or social work/care.

The report findings received mixed reception, with varying degrees of acceptance and subsequent joint/collaborative actions for delivery with variable progress, depending on case.

Irrespective of route, the acceptance and progress appeared to be significantly influenced by two key factors, a) the 'attitude and approach' of the report introduction by the introductee, and b) the 'acceptance and the will' of the professional recipient. Engagement and communication a critical component.

Opportunity for informed actions and interventions were enhanced when the engagement and direct conversations were more equitable (*an alternative term usefully applied elsewhere is 'horizontal'*) between individual, parent carer and professionals as well as between professional and professional. It was reported that on these occasions, individualised reports, professionally rated with clinical oversight were collectively viewed as independent, holistic, and inclusive. Adding further value and appeared to deliver the absence of professional or subjective bias i.e., non-system, non-professionally biased, a **key** contribution for moving forward.

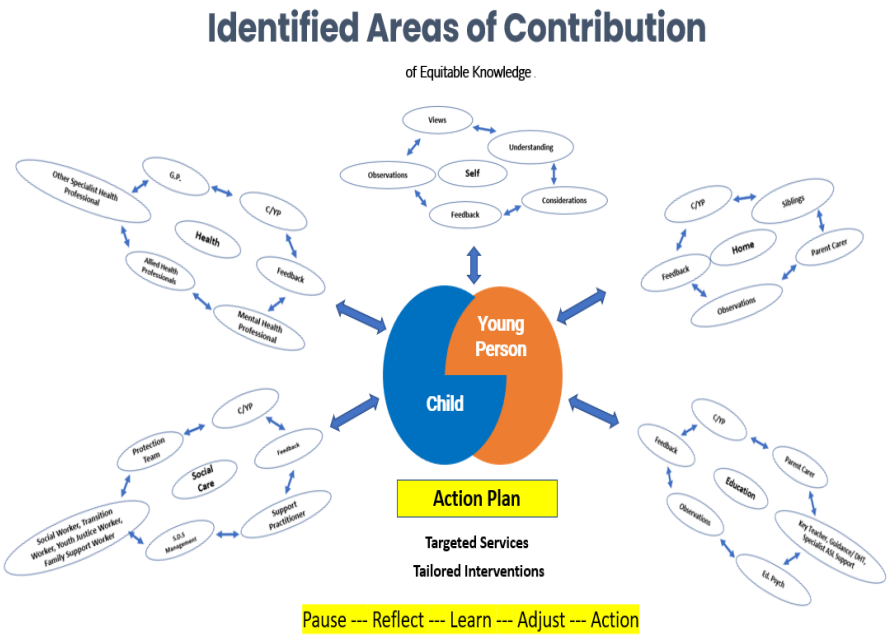
Agreed co-produced actions were progressed timeously seemed to be influenced by buy-in via one of the following routes (see illustration below):



- via education where the educational professional viewed the report as adding value, bought-in and in parallel connected with health and social work.
- Via Health, where the health professional viewed the report as adding value and partnered with either education or social work, but not in parallel.
- Via social work where the social worker viewed the report as adding value and partnered with either education or health, but not in parallel

The most person centred, and informed actions included the DAWBA Report and Advocacy Response in enhancing the creation of a person-centred framework within the action plan for overall wellbeing and support. Inter-agency practice in respect of GIRFEC became a natural process of this shared approach.

Outcome and Learning Point: From feedback, harmonisation for horizontal conversations have five key contributing dimensions. They are 'self,' 'home,' 'school,' 'health' and 'social work/care' each adding valuable insights and contributions as appropriate to intervention stage, and as such to an individual's support plan, keeping the child or young person at its core, (illustrated below), all within existing frameworks.



Outcome: By nature of its framework and thoroughness. We can see from the DAWBA suggestions from the consideration table, an individual's DAWBA reports does provide a comprehensive individualised insight to support informed decision making 'positive next steps' inclusive approach for inter-agency and partnership planning with individual and family, in shaping one of the following plans:

- Additional Support Plan
- Childs Plan,
- Individual Education Plan
- Individual Wellbeing Plan, *and the more legally obligated*,
- Coordinated Support Plan,

all within an existing system. Therefore, not reinventing the wheel, merely using a different tool for an earlier comprehensive and more holistic overview, becoming better, and enabling better informed earlier targeted and tailored interventions, supporting mutli-disciplinary action in timely parallel accord.

Outcome: Our participant and their families via self-directed partnerships with professionals were therefore more able to deliver a positive inclusive approach, which often, is needed to bridge the medical and social thinking models to meet an individual's needs and optimise integration of service delivery.

Irrespective of plan type, content is more important along with **pause - measure – reflect – learn – adjust - action**- repeating regularly, but not necessarily routinely, thus drawing in value not just in respect of GIRFEC but also within Scotland's mental health strategy 2017-2027 [32] "…. six quality dimensions - person-centred, safe, effective, efficient, equitable and timely."

It is however, of critical importance that a plan is joined up, especially where there is an 'inter-agency' component that is beyond a partnership between education and individual and family.

All plans bring challenges over and above administrative. Challenges can be down to interpretation of legislation, guidelines, policy, or simple people interface. They have just as much to do with engagement, communication, training and more.

From discussions within the pilot, it became clear, whilst a Coordinated Service Plan brings a stronger legal obligated commitment, they can be cumbersome, complex, and bureaucratically challenging to deliver i.e., chair/HT having to re-convene the entire Team Around the Child (respective diary commitments notwithstanding), minute and agree updates/revisions/ exclusions etc. Due to this, often limiting the expedience of flexibility and progress when considering – **pause - measure – reflect – learn – adjust – action**, depending on individual need they are and can be on occasions the only consideration.

One type of plan may bring more outcomes driven benefit than another for example an Additional Support Plan.

Within South Lanarkshire for example, we are told, there appears to be a growing preference for an 'Additional Support Plan. The ASP is a holistic plan. It provides an overview of the range of interventions and support, which have been agreed to meet the child or young person's additional needs. It includes a number of parts which can be used to tailor the plan to the needs of the pupil. See appendix.

This type of plan may be more beneficial for the overview of delivering outcome/s, as it is less onerous, and less prescriptive and facilitates greater flexibility and ongoing iterations which are responsive to evolving support needs.

In determining the type of plan, we strongly suggest this is considered carefully, by all involved and reiterate, content, actions, and outcomes for an individual should be the forefront and central to all.

Outcome: It has become evident we can build to a degree on the work of NSPCC [4] report of 2014, as well as contributing to

- Listening to and empowering of children and young people and their families
- Improving placing of children's and young people's relationships at the centre of individualised person-centred partnership approaches promoting horizontal communication
- Dissemination of a more informed, holistic wellbeing overview of a child or young person, whilst acknowledging multi-disciplinary formulation
- Enablement of targeted service provision with person-centred tailored interventions
- Additional and or substitution of good, informed practice in partnership decision making, raising the relevant 'weighting' of self-defined and parent carer contributions, reducing 'distancing' practices and terminology.

Outcome: By nature of positive partnership approaches, this develops a dialogue about co-creating resources, co-designed and collaboratively delivered by all stakeholders in all sectors, … bottom up, instead of top down, with advocacy support as appropriate.

We must recognise the challenges associated to advocacy and supported by the actioned advocacy numbers, not surprising, given the know lack of access to Independent Advocacy, and the increasing importance of and benefits from peer advocacy and parental/practitioner advocacy.

Equally recognised within The Promise [23]

> *"Peer advocacy has proven to support families to navigate their way through a complex system"*

and within All our Children All Their Potential [5]

> *"Currently the visibility of individual children and young people rely on the determined advocacy of parents and carers or representational groups"* …

Outcome: The following achievements for some, within this project:

- Timely sharing of one report providing a more holistic wellbeing overview
- Effective multi-disciplinary practice beyond the pilot team
- Joined up connected -cohesive practice between multi-disciplinary professionals
- Connected inclusive individualisation
- Reduced adversarial conversations
- Seventy four percent actionable rate
- Service Targeting
- Tailored Interventions
- Timely – expedient interventions

Outcome Benefit: When a young person themselves tells us their perception -

> ***"Know me Better" "Enables us all More"***
>
> 12-year-old

Outcome Benefit: When Children's panel members tell us -

> ***"A report like this would enable us to make better more informed decisions"***
>
> Childrens Panel Members

Outcome Benefit: When a parent realises what can happen with their child and states -

> **"I wish all young people could have access to this project." "… helping schools and parents …."**
>
> A Parent

Outcome Benefit: When a teacher state it is benefits -

> **"Exceptional pointer for us teachers, many who you have no formal training in child or adolescent mental health.**
>
> A teacher

Potential benefit for future **Outcomes** -Professional talk to professional and in one discussion, they consider the implications and potential benefit of using the DAWBA, as part of their assessment and information garnering process, when it comes to addressing some of the challenges within the **Inclusion as Prevention** approach – 'Windows of Opportunity' in CYCJ info sheet 91 [35]

> *"Windows of opportunity can be missed for a number of reasons, and it is important to acknowledge that despite individual and service efforts, the constraints of the system are often a factor in missed opportunities to intervene. Despite substantial support for prioritisation of preventative and early intervention* efforts (Christie Commission, GIRFEC, Whole System Approach, Justice Vision, and Priorities) ..... faces a lack of strategic investment ..... which *has led to substantial loss and interventions...."*

Indicative statement for **benefit, outcome,** and **impact** - It comes as a surprise when professionals tell us

> ***"This could be 1000 times better than what we have at present"***
>
> Team Leader Social Work

Outcome: A consideration of the pilot was information about how SDQ/DAWBA online questionnaire enabled added value at input stage. We were informed it could have

- greater use of visual supports
- enhanced section on environment and sensory
- an option to inform a question does not apply
- input from a speech and language therapist for questionnaire redesign for user friendliness
- improved accessibility for 'Apple' technology
- could be more user friendly if an APP
- inclusion of a questionnaire for social care practitioners and professionals

Outcomes: Having listened, those self-directed partnership actions are a contributory component to and impact positively on delivery within the following policy areas, answering our lesser yet just as important considerations --

- Getting it Right for Every Child, [7]

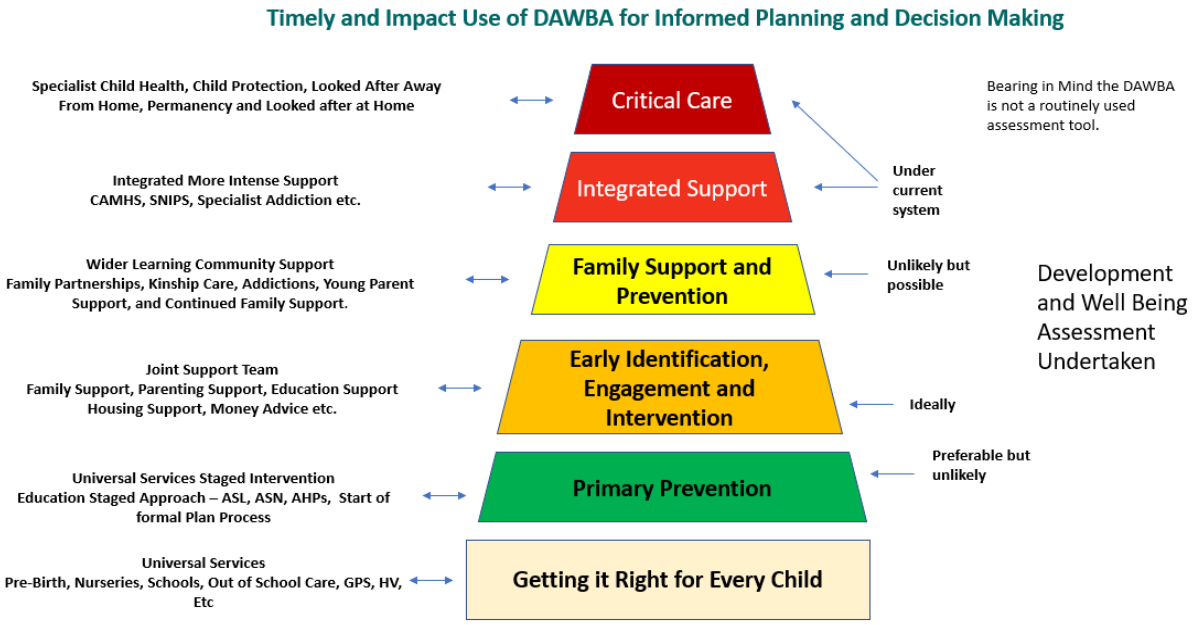
- The Promise [23]
- The Accountability Gap [24]
- All Our Children All Their Potential [5]
- The Additional Support for Learning Action Plan (ASLIP) [25]
- The Neurodevelopmental Specification: Principles and Standards of Care [29]
- United Nations Convention on the Rights of the Child [9]
- The Equality Act [30] and UNCRPD [31]
- The National Mental Health Strategy 2017-2027 [32]
- The COVID Recovery Strategy – A Fairer Future [33]

At a pilot team meeting, there was a discussion around the benefit and impact of the DAWBA for assessors, both raters and clinical psychologists. The discussion concluded as both were in agreement that

"Subject to a comprehensive set of completed questionnaires both rater and psychologist would be confident in the efficacy of DAWBA, positively suggesting, if said information was readily available it could, potentially and positively reduce the face-to-face time required with a client.

We also discussed where the DAWBA could fit within existing practice and whether or not it was contradictory of existing assessment tools. "The general consensus from the assessors in the team it was complimentary to and depending on practitioners' differential knowledge experience it could be used as a replacement."

There was the belief the DAWBA it could be used anytime in a process, but the earlier the better. The diagram below illustrates this in relation staged intervention process.



"Our son's DAWBA report was very informative and helped us to understand our son better."

"We feel like the current diagnostic process is lacking in depth as it does not ask the number of relevant questions the questionnaire did and also the questionnaire lacks the face-to-face contact needed to really understand the child."

"In our opinion, if the questionnaires were filled in and scored prior to the actual face to face assessment visit, this would be more beneficial for the everyone, more expedient and more comprehensive with the additional benefits of a) less stress for individual and family, and b) improved directional pointers for other non-diagnostic professionals."

Outcome and Overall Learning Point for Users, their families, and their supporters:

In Scotland a diagnosis is not a requirement for either ASL/ASN, as such, the benefit of the DAWBA Indicative Individualised Profile report, where positively received, has equitably empowered individuals, parent carers, practitioners and professionals to have a more horizontal conversation about identifying, planning and delivering either interventions and or further more specific assessments more expediently, supporting targeting of service provisions and tailoring interventions.

Overall Outcome: The Development and Well Being Assessment instrument when used to provide indicative individualised profile can have beneficial impact on person-centred inclusion, planning on targeting services with tailored interventions, across a wide range of integrated - interagency supports, with positive benefits for individual, families, practitioners, and professionals alike, with proficiency contributing to a societal return on investment.

Overall Learning Point for the assessment tool: Greater use of supportive visuals, along with an improved section on environmental and sensory along with an additional questionnaire for social care practitioners.

From the data, evaluation feedback and case studies we are able to deduce**:**

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.

Conclusions

The pressing need for an evidence-based, timely, accurate and unbiased assessment process has been articulated in several Scottish Government and Audit Scotland reports highlighting the state of current diagnostic and post diagnostic services being 'unfit for purpose' due to wasteful, complex, convoluted and time-intensive approaches. This predicament is compounded by persistently elevated 'rejected referral' rates from targeted and clinical services.

Service users, their parent carers and autism-informed professionals in all sectors have continued to voice concerns about inordinate waiting times, and lack of pre-, mid and post diagnostic services, designed collaboratively by communities of interest who know best what is needed.

As you will gather from the current analysis, this pathfinder pilot has demonstrated what a broader, practice-based application of the SDQ/DAWBA could potentially offer individuals, families, and support services by identifying indicative support needs at a much earlier stage than happens at present avoiding wasted time and resources **'throwing darts in the dark'** at poorly or incompletely defined presenting issues. It would also expedite deployment of timely, cost-effective, and tailored supports initiated 'responsively' as opposed to 'reactively.' "There comes a point where we need to stop just pulling people out of the river (reactively). Some of us need to go upstream and find out why they are falling in (responsively)" (Desmond Tutu).

The SDQ/DAWBA offers an approach that aims to fulfil many of the strategic aspirations set out in Scottish Government policy spanning the past 4 years. This is especially relevant in the current post-COVID recovery period when there is consensus that **'things need to change'** if we are to create a fairer future for Scotland's neurodiverse and neurotypical people alike.

This portion of the paper seeks to briefly link the findings and analysis of the pilot findings with the overarching vision outlined within broader strategic and policy developments, principally spanning 2018 to the present.

In 2018, having been commissioned by the Scottish Government and 4 years of intensive data interrogation by two prestigious economic research teams, co-located within the London School of Economics and Strathclyde University, the publication of the **Micro-Segmentation Report** [14] concluded that unremitting systemic and structural inequalities continue to be faced by autistic individuals and their families. The identified barriers are unaltered despite a ten-year **Scottish Strategy for Autism**. [36] When 'escapable' and 'inescapable' costs relating to both quality-of-life outcomes, and lost revenue to Scotland's economy were analysed, the MS report concluded that costs associated with autism account for more than Scotland's five 'big killers' (Diabetes, Stroke, Cancer Heart Disease and Dementia) almost combined, yet corresponding levels of investment attract only a small fraction of the funding invested in researching and intervening in the other 'big five'. The Micro segmentation report lauded the 'invest to save' approach demonstrating that for each **10% reduction** in escapable costs achieved through evidence-based interventions,

savings of **£223 million per annum** (at 2018 rates) could be accomplished. Two central tenets of interventions proven to be most effective were parent-mediated programmes and the wider availability **of self, group, peer, and independent professional advocacy services.**

Both the autism and neurodevelopmental community and professionals agree that uniformed solutions do not solve problems, and the potential application of the SDQ/ DAWBA as a non-clinical early identification tool, albeit still overseen and quality assured by suitably qualified psychology personnel, would make a significant contribution to the identification of unmet support needs and subsequent co-creation of bespoke interventions at a much earlier stage. By doing so, significant savings in both quality of life and lost revenue will be made in relation to costs. It is worth noting that whilst the pilot was primarily focused on Neurodiversity, its application is significantly wider identifying mental health and wellbeing issues for all neurotypes.

Viewed as a whole, the aspirations and action points contained within the selected Scottish Government publications demonstrate that the pilot represents a successful application of the shared and embedded principles within them all principally; empowerment, inclusivity, collaboration, co-production, authentic partnership, needs-led targeted and early, non-stigmatising interventions.

For the sake of brevity, the 'common threads' articulated in the following 10 strategic documents 'The Promise' [23], 'Learning/Intellectual Disability and Autism Towards Transformation [37] ,'The Accountability Gap' [24] , 'All our Children All Their Potential' [5], 'The Additional Support for Learning Action Plan (ASLIP)' [25], 'The Independent Review Autism and Learning Disability of the Mental Health Act Scotland (IRMHA)' [38], 'The Neurodevelopmental Specification: Principles and Standards of Care' [29], 'The Blake Stevenson Review of the Scottish Strategy for Autism' [39], 'The National Mental Health Strategy 2017-2027' [32] and 'The COVID Recovery Strategy – [33] A Fairer Future', can be supported both systemically and individually by utilisation of SDQ/DAWBA.

All documents explicitly reference the Scottish Government mandate to ensure full participation and inclusion by users and carers at the consulting, legislating, and implementing stages. By ensuring these 'quieter voices' are heard, policies and action plans will truly reflect the 'lived experiences' of those in receipt of services, infusing draft policy with the principles contained in the ECHR, [40] UNCRC [9] and, UNCRDP. [31]

The pilot findings drawn from case studies and respondent feedback and evaluation questionnaires demonstrate that children and young people, their parent carers, families, and professionals alike believe that this highly accurate, timely and cost-effective process can result in the diminishment of inordinate waiting times, delayed supports, ineffective interventions, and adversarial relations between those who seek services and those who provide them. Horizontal relations are a natural outcome of the entire process and facilitate meaningful, person-centred collaborations for all stakeholders.

The pilot has also established that for example, autism-informed practice is simply good anti-discriminatory practice for all, whether neurodiverse or neurotypical. Applying a timely assessment process which reduces professional bias to a minimum whilst placing equal

currency on the contributions of participants and their parent/carers, creates buy-in from all within the entire process. The Innovatively Individualising Triage Pilot has demonstrated that real and sustained change can and does happen when 'top-down' approaches give way to 'bottom-up' collaborations between all stakeholders, especially when there is a readiness on the part of professionals formerly tasked with the exclusive role of assessment, to 'share' these processes with recipients of supports and services and their networks of support, enabling multi-disciplinary approach in parallel as oppose to silos.

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

Recommendations and Suggestions

As we have identified, the assessment instrument used in this pilot has proven helpful for individuals parent carers and professionals alike with equity, due diligence, and compliance.

When there is an 'appreciative' will power and equitable partnership between individual, parent carer/legal guardian and professional/s it becomes easier in the co-creating an individualised person-centred plan of action, enabling timely, targeted, and tailored interventions to be delivered.

From this small exploratory observational pilot project, we would suggest/recommend as part of an improving partnership approach –

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.

Thank you and Acknowledgements

The pilot team would like to acknowledge thank the following their contributions –

The Participants

Their Families

Their Supporters

The Nominating Partners of

AISee -Advocating, Identifying, Solutionising, Empowering and Energising

ARCH - Autism Coordination Resource Hub

CLC – Neurodevelopmental Educational Consultancy

COAST – Champions of Autism Spectrum Together

Neurodivergent Voice –

RANP – Renfrewshire Autism and Neurodevelopmental Project

SAIL – Supporting Autism in Lanarkshire

WIO – Work It Out

The Enablers

These are the people the pilot team do not necessarily know by name, who did a fantastic job by providing

a) Enabling support for participants to complete their questionnaires.
b) Enabling and supporting individuals and families to self-direct the information within their reports
c) Enabling practitioners and professionals who acted upon the information shared and either put in place a new intervention or adjusted an existing
d) Enabling practitioners who drove forward further explorations for an individual as identified.

Youth in Mind for their generous support free access to SDQ and Development and Wellbeing Tool for this pilot project, and of course their initial guidance consideration in respect ethics and processes and clinical oversight requirements.

SLC- South Lanarkshire Council and **SLHSCP** – South Lanarkshire Health and Social Care Partnership for supporting this project via their staff. Provision of Consultant Clinical Psychologist. Above the senior management team for insight and vision.

NHS Lanarkshire For positively responding to SLHSCP request on behalf of the pilot project for providing Dr Lucie Risk, Consultant Clinical Psychologist to provide clinical oversight of and input to the DAWBA rated Assessments for the duration of the project.

Val De Sousa Chief Officer South Lanarkshire Health and Social Care Partnership, (now retired) for her recognition and commitment to getting this project moving and for writing the forward to report.

Key Team

Thom Kirkwood PhD. GA. FRSA. FIntAPA. FITOL. MInstCPD. AIEP.

Project Coordinator and Co-Author.

An advocating Inclusion specialist, change agent and skill enhancer, with 50 years third sector and strategic experience,(p.t.v) 15 years advocating practice within the neurodevelopment sector. He has served and contributed to many local, national, and international forums on advocacy, autism, education, GIRFEC, neurodiversity and social care, including many positions associated to Scottish Strategy for Autism. He has authored a number of independently accredited training courses/workshops on advocacy, transitions, employability, and neurodiversity inclusion. International Advocacy Practitioners Association he has served as President, Chair Advocacy Practitioner Education and Wellbeing Committee, and currently Chair of Research and Reflective Learning Committee. From his international work identified the seventeen epistemic challenges associated to autism. Rotational co-lead the ND Gifts Movement Europe Chapter and the Independent Advisor to Renfrewshire Autism and Neurodiversity Project. He also chairs and coordinates the six DiAC's.

Bill Colley, BA. PGCE.

Rater, and Co-Author

Bill is a writer, teacher trainer and educational consultant, trained in diagnostic assessments in both ADI-r and ADOS, and a trained rater for DAWBA. He spent his career in both independent sector before becoming the principal of residential special school and He is in local government as a Service Manager. As service manager with responsibility for additional support needs and contributed at a local level to an ADHD support group, the NHS Autism Assessment Pathway, and to the National Autism Strategy Reference Group (Scotland). He is also Chair of Scottish ADHD charity and Vice President UKAP.

Ramon Hutchingson BA, PQ, CQSW, Project Link South Lanarkshire & Co-Author

As Co-ordinator of South Lanarkshire's Autism Resources Coordination Hub (ARCH) for the past 6 years, and a registered Social Worker for 34 years I represent the Authority in various national forums including Lead Officer Collaborative meetings facilitated by Autism Network Scotland between 2016-2022.During one ANS meetings in 2019, an assessment tool called the Development and Wellbeing Assessment (DAWBA) was presented. Me and many other Lead Officers were immediately struck by the potential applications of this tool, especially supporting autistic children and young people. Throughout my career as a front-line social worker, a timely, structured, evidence-based, cost-effective, and highly accurate assessment approach which also offered bias-free information would have been an invaluable tool. As a result of my interest, I collaborated with colleagues. This eventually evolved into the Innovatively Individualising Triage Pilot.

Dr. Lucie Risk. D.Psych. Clinical Oversight Assessments

Is a Consultant Clinical Psychologist within NHS Lanarkshire. Dr Risk was given allocated time to provide clinical oversight of the DAWBA rated assessments as per a request from our pathway partner South Lanarkshire Health and Social Care Partnership.

Associate Contributions

From the start of this project there was regular associate contribution representing two groups directly associated to opportunities and social inclusion.

This contributory input in term of shaping the content and structure of the process, inclusion and the report overview was from the offset hugely important as it supported the fundamental component of UNCRC Child and Young persons Rights plus the principle fo self-direction.

We would like to thank

Andrew Cross, BA (Hons) Supported Employment Team/ Social Inclusion Project South Lanarkshire

Fiona Milne, AMIntAPA, Project Manager, Renfrewshire Autism and Neurodiversity Project.

Glossary of Terms

Abbreviation/Acronym	Term	Description/Meaning
A		
ADD	Attention Deficit Disorder	Formal term, *now rarely used*, covering a range of behavioural disorders occurring primarily in children, such as but not limited to, poor concentration, hyperactivity, and learning disabilities.
ADHD	Attention Deficit Hyperactivity Disorder	A condition that affects people's behaviour. For example, fee restless may have trouble concentrating and may act on impulse.
ADI-r	Autism Diagnostic Interview Revised	A widely used diagnostic algorithm in determining whether children and young people have autism spectrum disorder.
ADOS	Autism Diagnostic Observation Schedule	A semi-structured, standardised assessment of communication, social interaction, play or imagination use of materials for individuals who may have been referred for an autism assessment.
AD	Attachment Difficulties	These are when an individual has challenges with sustained attention at a developmentally appropriate level.
	Advocacy	Advocacy involves promoting the interest of someone or a group of people. Advocacy is also about helping people find their voice and supporting them to have that heard. An advocate is a person who person who argues

		for recommends or supports a cause or policy. There are key types of Advocacy, Community, Peer, Self, Collective and 1-2-1, with the latter strongly applicable in Scotland (Project Country) to statutory provisions within legislation.
ARFID	Avoidant and Restrictive Food Intake Disorder	Feeding disturbance as manifested by persistent failure to eat with significant failure to gain weight or significant loss of weight. Previously known as Selective Eating Disorder.
AR (This Project)	Advocacy Response	The advocacy response in this project was designed to encourage and guide individuals their families and practitioners to have more inclusive conversations that support co-created solution.
	Agoraphobia	Extreme lor irrational fear of entering open or crowded places, of leaving one's own home, or being of being in places from which escape is difficult
AHP	Allied Health Professional	Are a diverse group of clinicians who deliver to patients and clients across a wide range of care pathways. For example, but not limited to Speech and Language Therapist, Occupational Therapist etc.
	Anorexia	A serious eating disorder and mental health condition.

Anxiety General	Anxiety General	A feeling or worry, nervousness or unease about something with an uncertain outcome.
ASC	Autism Spectrum Condition	This is a term of increasing use, used by some instead of autism spectrum disorder
ASD	Autism Spectrum Disorder	A complex developmental condition involving persistent challenges with social communication, restricted interests, and repetitive behavior.
ASP	Additional Support Plan	The ASP is a holistic plan. It provides an overview of the range of interventions and support which have been agreed to meet the child or young person's additional needs. It includes a number of parts which can be used to tailor the plan to the needs of the pupil.
B		
BD	Bipolar Disorder	Is a mental health condition that affects your moods, which can swing from one extreme to another.
	Bulimia	Bulimia is an eating dorser that causes one to eat substantial amounts of food at one time then get rid of it.
C		
CAMHS	Child and Adolescent Mental Health Services	The name for the NHS services that assess and treat young people with emotional, behavioural, or mental health difficulties.
CBT	Cognitive Behaviour Therapy	Is a talking therapy that can help you manage

		your problems by changing the way you think and behave.
CIHA	Common Interest Holistic Advocacy	An individualised advocacy approach which encourages a common holistic practice between individual, family, and practitioners via co-production.
C-GAS	Childrens Global Assessment Scale	A Numeric scale used by mental health clinicians to rate the general functioning of youths under the age of eighteen
	Comorbid	Denoting or relating to diseases or medical conditions that are simultaneously present in a patient.
CD	Conduct	A group of behavioural and emotional problems characterized by a disregard for others.
CP	Child's Plan	Is considered and developed in partnership with the child, their parent(s) and the services involved. Every plan will include and record: information about the child's wellbeing needs including the views of the child and their parent(s) details of the action to be taken.
CP	Child Protection	Is part of the safeguarding process. It focuses on protecting individual children identified as suffering or likely to suffer significant harm.
CP	Children's Panel	Is a group of volunteers who make legal decisions with and for children and young

		people in *children's hearings.*
CPTSD	Complex Post Traumatic Stress Disorder	Is a condition where you experience some symptoms of PTSD along with some additional symptoms, such as: difficulty controlling your emotions. feeling incredibly angry or distrustful towards the world
CSP	Coordinated Service Plan	Is a tool used to get all the parties, two or more agencies, involved in a child's care where benefits at *Coordinated Services Planning* level can be extremely helpful in numerous ways in achieving a coordinated service approach.
D		
DAWBA	Development and Wellbeing Assessment	The DAWBA is a package of interviews, questionnaires and rating techniques designed to generate ICD-10 and DSM-IV or DSM-5 psychiatric diagnoses on 2–17-year-olds. DAWBA covers the common emotional, behavioural and hyperactivity disorders, without neglecting less but sometimes more severe disorders.
	Developmental Delay	Refers to a child who has not gained the developmental skills expected of him or her, compared to others of the same age. Delays may occur in the areas of motor function, speech, and language, cognitive, play, and social skills.

	Diagnostic Overshadowing	Diagnostic overshadowing occurs when one condition is diagnosed but other coexisting conditions are overlooked.
	Diffability	Someone who has different abilities. People who do the same jobs as other people, they just do them differently.
DX	Differential DX (Diagnosis)	A *differential diagnosis* is a list of conditions that share the same symptoms that you described to your healthcare provider.
	Disability Model	A model that proposes that what makes someone *disabled* is not their medical condition, but the attitudes and structures of society. See also Social Thinking Model.
DMDD	Disruptive Mood Dysregulation Disorder	Is a childhood condition of extreme irritability, anger, and frequent, intense temper outbursts. DMDD symptoms go beyond a being a "moody" child—children with DMDD experience severe impairment that requires clinical attention.
DSH	Deliberate Self Harm	A prominent mental health concern among adolescents whereas the name suggests infliction of harm to oneself.
DSM V	Diagnostic Statistical Manual of Mental Disorders – V denotes Fifth Version.	Is the standard classification of mental disorders used by mental health professionals in the

		United States and by some in other countries.
E		
	Elimination Disorders	*Elimination* disorders occur when children have difficulties in relieving themselves or do so in inappropriate places, after a certain age.
	Epigenetics	*The study of the interaction between genetic and environmental factors in development.*
	Executive Function	Set of high-order mental skills that include working memory, flexible thinking, and self-control. We use these skills every day to learn, work, and manage daily life. Trouble with executive function can make it hard to focus, follow directions, and handle emotions, among other things.
F		
FDIA	Factitious Disorder Imposed on Another	People with *factitious disorder imposed on another* (*FDIA*) provide inaccurate information about an illness in another person.
	Feeding Difficulties	This is a broad term used to describe a variety of feeding or mealtime behaviours perceived as problematic for a child or family. This may include behaviors such as: Picky eating. Food fussiness.
G		

GP	General Practitioner	General practitioners treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment.
GIRFEC	Get it Right for Every Child (Wellbeing Indicators)	Getting it right for every child (GIRFEC) supports families by making sure children and young people can receive the right help, at the right time, from the right people. The aim is to help them to grow up feeling loved, safe, and respected so that they can realise their full potential. Incorporating the wellbeing indicators of Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, Included.
H		
	Hyperactivity	Usually refers to constant activity, being easily distracted, impulsiveness, inability to concentrate, aggressiveness, and similar behaviors. Typical behaviors may include Fidgeting or constant moving.
	Hyper-acuity	Greater than normal acuteness of a sense.
	Hypo-acuity	Decreased sharpness of sense.
HoNOSCA	Health of Nation Outcome Scales for Children and Adolescents	Recently developed measure of outcome for use in child and adolescent mental health services on general health and social functioning.
I		

ICD 11	International Classification of Diseases (11 revision) World Health Organisation	ICD serves a broad range of uses globally and provides critical knowledge on the extent, causes and consequences of human disease and death worldwide via data that is reported and coded with the ICD. Clinical terms coded with ICD are the main basis for health recording and statistics on disease in primary, secondary and tertiary care, as well as on cause of death certificates. These data and statistics support payment systems, service planning, administration of quality and safety, and health services research. Diagnostic guidance linked to categories of ICD also standardizes data collection and enables large scale research
ID	Intellectual Disability	Is significantly below average intellectual functioning present from birth or early infancy, causing limitations in the ability to conduct normal activities of daily living.
IEP	Individualised Education Programme	Used by many schools as a planning, teaching, and reviewing tool for children and young people with special educational needs. (SEN).
	Intervention	An ***intervention*** is a carefully planned process that may be done by for example an individual, family and

		friends, in consultation with a doctor or professional to improve, protect, support an individual's outcomes in health, social care, education etc.
	Intervention Stage (In Scotland we have four levels depending on severity)	The staged intervention process provides a framework for educational establishments to identify, assess and plan to address the additional support needs of all children and young people. This may include one or more from social work, allied health professionals, educational psychologist, CAMHS.
L		
	Lead Professional	Is someone employed by one of the services involved in supporting the child and family. If the child's needs are assessed as more complex and require considerable help from specialist services or there is a legal duty to work with the child and family, a lead professional will be identified.
LD	Learning Disability	Are disorders that affect the ability to understand, or use spoken or written language, do mathematical calculations, coordinate movements, or direct attention.
LIAM	Low Intensity Anxiety Management	Is the term used for supports associated to mild or moderate

		anxiety where supports are delivered via the model of LIAM see below.
LIAM	Let us Introduce Anxiety Management	LIAM is a staged training offer intended to develop skills in the delivery of a CBT-informed approach for the treatment of mild-moderate anxiety symptoms in children and young people.
M		
	Medical Model	The medical model is a biopsychosocial model assessing a patient's problems and matching them to the diagnostic construct using pattern recognition of clinical features. Diagnostic constructs allow for researching, communicating, teaching, and learning useful clinical information to influence clinical decision-making.
N		
	Named Person GIRFEC	This contact will be someone whose existing role already involves providing advice and support to families. As each child grows up, their contact will change, with support usually provided by a: health visitor from birth to school age, head teacher or deputy during primary school years, head teacher, deputy, or guidance

		teacher during secondary school years. A family may be offered direct support from their named person or access to relevant services offered by the NHS, local authorities and third sector or community groups.
	Named Person (Mental Health)	A ***named person*** is someone who can look after your interests if you are cared for or treated under ***mental health*** legislation.
	Neurodevelopmental Condition	Are multifaceted conditions characterized by impairments in cognition, communication, behavior and/or motor skills resulting from abnormal brain development.
	Neurodivergence	Is the term for people whose brains function differently in one or more ways than is considered standard or typical.
	Neurodiversity	Describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits.
	Neurokin	A word used to describe someone who is the same neuro-type as you.
NDD	Neurodevelopmental Disorders	NDDs are defined as a group of conditions with

		onset in the developmental period, (i.e., pre-birth, during birth, and/or during exceedingly early development) inducing deficits that produce impairments of functioning. NDDs comprise intellectual disability (ID); Communication Disorders; Autism Spectrum Disorder (ASD); Attention-Deficit/Hyperactivity Disorder (ADHD); Neurodevelopmental Motor Disorders, including Tic Disorders; and Specific Learning Disorders.
O		
OCD	Obsessive Compulsive Disorder	A common mental health condition where a person has obsessive thoughts and compulsive behaviours which intrude on or impair daily function. OCD can affect men, women, and children. Some people start having symptoms early, often around puberty, but it usually starts during early adulthood.
ODD	Oppositional Defiant Disorder (Oppositional)	A type of behavior disorder. It is mostly diagnosed in childhood. Children with ODD are uncooperative, defiant, and hostile toward peers, parents, teachers, and other authority figures. They are more troubling to others than they are to themselves.
OT	Occupational Therapist	An occupational therapist helps people

		of all ages overcome challenges completing everyday tasks or activities – what we call 'occupations' to improve their health and wellbeing.
P		
	Panic	Panic disorder are a type of anxiety where one has regular had sudden attacks panic or fear. A sudden overpowerment of extreme anxiety.
PDD	Pervasive Development Disorder	Refers to a group of disorders characterized by delays in the development of socialization and communication skills, and which affect all aspects of daily function.
PTSD/cPTSD	Post-Traumatic Stress Disorder /Complex Post Traumatic Stress Disorder	Is a mental health condition that is triggered by a terrifying event — either experiencing it or witnessing it. Symptoms may include flashbacks, nightmares, and severe anxiety, as well as uncontrollable thoughts about the event.
	Psychosis	A severe mental disorder in which thought, and emotions are so impaired that contact is lost with external reality.
Q		
QoL	Quality of Life	is defined by the World Health Organization as an individual's perception of their position in life in the context of the culture and value systems in

		which they live and in relation to their goals, expectations, standards, and concerns.
R		
RRS	Ruminative Response Scale	A self-report measure of describing one's responses to depressed mood.
S		
SALT	Speech and Language Therapist	Is a therapist who provides treatment, support and care for children and adults who have difficulties with communication, or with eating, drinking, and swallowing.
SDQ	Strength and Difficulties Questionnaire	The Strengths and Difficulties Questionnaire (SDQ) is a brief behavioural screening questionnaire about 3–16-year-olds. It exists in several versions to meet the needs of researchers, clinicians, and educationalists.
	Separation Anxiety	A type of mental health problem. A child with SA worries a lot about being apart from family members or other close people. The child has a fear of being lost from their family or of something bad occurring to a family member if he or she is not with the person.
SET	Supportive Enabling Technologies	Are apps or technology supports that enable and individual to have improved choice, control independence and supports their daily living.
	Social Awkwardness	Means that we have trouble communicating

		with others, especially in a social setting. Large groups of people or social gatherings become almost impossible for us to manage, and as a result, it can limit our life experience.
	Social Phobia	Is a long-term and overwhelming fear of social situations.
	Specific Phobia	An intense, irrational fear of something that poses little or no actual danger.
SpLD	Specific Learning Difficulties	Difficulties that impair the learning process such as dyslexia or dyscalculia
T		
TAC	Team Around the Child	Team Around the Child is a proportionate approach to meet the needs of the child and is facilitated by the Named Person and Lead Professional (if there is one) from early intervention stages up to Child Protection Team Around the Child meetings
	Tics	Tics are fast, repetitive muscle movements that result in sudden and difficult to control jolts or sounds.
TP	Transition Plan	A document that outlines what you want to achieve in the next few years - and what support you will need to live as independently as possible. It covers every aspect of your life, including for example but not limited to – education, employment, health, housing, social care.

	Tourette Syndrome	A condition that causes a person to make involuntary sounds and movements called tics. It usually starts during childhood, but the tics and other symptoms usually improve after several years and sometimes go away completely.
U		
UNCRC	United Nations Conventions of the Rights of the Child	A legally binding international agreement setting out the civil, political, economic, social, and cultural rights of every child, regardless of their race, religion, or abilities.
Y		
YP	Young Person	A person from 14 to 17 years of age.

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Appendix i

Full Dawba Report Sample

The following anonymised sample has been included with consent from individual and family.

In the interest of safeguarding, it has also had oversight from social worker with reserved function.

Dawba ID and any other associated reference has been withheld.

Overview of Development and Well-Being Assessment

Dawba ID: Withheld

Details: Young Person -YP

INFORMANTS

ID	Informant	Date	Age	Gender	About
Hidden	Mother	25/05/2022	14	Male	YP
Hidden	Self	25/05/2022	14	Male	YP

SYMPTOMS, IMPACT AND DIAGNOSTIC PREDICTIONS

Predicted probability of disorder: high

	Mother		Self		Prediction	
	Symp	Imp	Symp	Imp	DSM	ICD
Autism Spectrum	++	+++			+	+
Separation Anxiety	+	+++	-		- -	-/+
Specific Phobia	+	+	-		-	-
Social Phobia	++	++	-		++	++
Panic	++		++	+++	++	++
Agoraphobia	++		-		+	+
PTSD	+++	+++	-		+	+
OCD	+	++	+	+++	+	+
BDD	-		-			
Generalised Anxiety	+		+		-	-
Depression	+++	+++	+++	+++	+++	+++
Deliberate Self Harm	++		++			
Bipolar	+++	+++	+			
Emotions at school						
Attachment difficulties						
Hyperactivity	+++	+++			++	+
Oppositional	+				+	+
Conduct	-		-		- -	- -
Anorexia / Bulimia	+		-		-	-
Tics	-		-		- -	- -
Psychosis			-			
Feeding difficulties						
Sleeping difficulties						
Elimination difficulties						
Other concerns	++		-			

CLINICAL DIAGNOSES ASSIGNED BY RATER

DSM-IV diagnoses

Autism
ADHD combined
Generalised anxiety

Other depression
??PTSD
Rated by: Bill Colley, 30/05/2022
Rater Comments
SUICIDE ATTEMPT NOTED AS POTENTIAL FUTURE RISK. Existing dx of ASD noted as is 'working dx' of ADHD. DAWBA profile supportive of both. Associated anxieties and phobias not rated as discrete disorders given existing diagnoses. PTSD possible given history. Bipolar not rated given absence of true mania and likely hyperactivity. Grand delusions probable rather than mania. OCD not rated as repetitive behaviors appear to provide comfort rather than being intrusive. SUGGESTIONS: 1. Continuing engagement with mental health services and monitoring, 2. Support for family to ensure resilience in managing complex difficulties, 3. Careful transition planning with suitable advocacy to ensure YP's needs inform decision-making, 4. Potential for ASD-adapted CBT approach to support YP's understanding of self and current difficulties, and to manage these, 5. Strengths-based approach to support with multi-agency collaboration.

Bill Colley, 08/07/2022

CLINICAL RATING OF SEVERITY

C-GAS = 40
Rated by: Bill Colley, 30/05/2022

HoNOSCA = 23
Rated by: Bill Colley, 30/05/2022

Background information

Dawba ID: Withheld

Details: Young Person

	Mother
Medical	
Bad general health	-
Speech or language problems	-
Visual impairment or blindness	-
Hearing impairment or deafness	-
Movement or co-ordination disorder	-
Enuresis	++
Encopresis	-
Epilepsy	-
Learning difficulties	-
Living with parents:	Both parents
Stressful life events in the last 12 months	
Serious accident	-
In hospital for serious illness	++
Death of parent, sibling or friend	++
Loss of close friendship	-
Family financial crisis	-
Parental separation	-
Family stresses	slightly raised
Unemployment	-
Financial difficulties	+
Home inadequate for needs	++
Neighbours or neighbourhood	-
Work	-
Time pressures	+
Tension with partner	-
Tension with ex-partner	-
Alcohol or drug use	-
Gambling	-
Parents' physical health	-
Parents' mental health	-
Other people ill, e.g. grandparents	+
Child's experience of family life	Liked and respected
Affirmation	
Gets love and affection	
Praised and rewarded	
Gets help and support when stressed	

Background information

Dawba ID: Withheld

Details: Young Person

close to average

+++

+++

++

+++

Supervision	+++
Rules	close to average
Clear rules	+++
Consistently applied rules	++
Discipline	close to average
Told off or corrected	+
Physical punishment	-
Non-physical punishment	+
Gets blamed unfairly	-
Special allowances	very high
Upbringing affected by child characteristics	+++
Very protected	++
Spends time alone	+++
Respondent under strain	20
Everyday feelings questionnaire (EFQ)	high
Not optimistic	-
Worried or tense	+
Not able to enjoy life	+
Tired or lacking in energy	+
Stressed	+
Negative self-image	++
Loss of interest	-
Not calm and relaxed	++
Very unhappy	-
Unable to cope	++
Respondent's partner under strain	
Everyday feelings questionnaire (EFQ)	
Not optimistic	
Worried or tense	
Not able to enjoy life	
Tired or lacking in energy	
Stressed	
Negative self-image	
Loss of interest	
Not calm and relaxed	
Very unhappy	
Unable to cope	
Services and other help	
From family and friends	++

Books or magazines	++
The internet	++
Telephone help-line	++
Self-help group	++
A teacher (including head or SENCO)	++
Special educational needs	++
Educational psychology	-
GP, health visitor	++
Paediatric professional	++
Mental health professional	++
Social services professional	-
Any psychotropic medication?	++

>> Open-ended comments: Mother

Informant's description of medication
YP has been taking methelphynadate and sertraline, he has just currently came off of this under the psychiatrist awareness this is a trial period of two weeks.

Strengths and Difficulties Questionnaire

Dawba ID: Withheld

Details: Young Person YP

	Mother 25.05.22	Self 25.05.22
Total difficulties score	29***	24***
Emotional symptoms score	10***	6**
Conduct problems score	2	4*
Hyperactivity score	10***	10***
Peer problems score	7***	4**
Prosocial score	4***	3***
Impact score	10***	5***

*=slightly raised; **=high; ***=very high (prosocial: *=slightly low; **=low; ***=very low)

Diagnostic Prediction from SDQs

Any disorder	probable	
Emotional disorder	probable	
Behavioral disorder	unlikely	
Hyperactivity disorder	possible	

Created on: 08/07/2022 10:45

Strengths and Difficulties Questionnaire

Dawba ID: Withheld

Details: Young Person YP

	Mother	Self
Emotional items		
Headache, stomach-ache	++	++
Worries	++	++
Unhappy	++	++
Anxious in new situations	++	-
Fears	++	-
Conduct items		
Irritable	+	++
Obedient	+	-
Fights, bullies	-	-
Lies, cheats	-	-
Steals	-	-
Inattention-hyperactivity items		
Restless	++	++
Fidgety	++	++
Poor concentration	++	++
Reflective	-	-
Good attention	-	-
Peer relationship items		
Solitary	-	++
Has good friend	-	++
Popular	+	+
Victimised	++	-
Relates better to adults than peers	++	+
Prosocial items		
Considerate	+	+
Shares	-	-
Helpful	+	+
Kind to younger children	+	+
Volunteers to help	+	-
Impact supplement		
Is there a problem?	Severe	Severe
Duration (months)	>12	>12
Distress	+++	+
Impact on family life	+++	+++
Impact on friendships	+++	+
Impact on learning	+++	+++
Impact on leisure	+++	++
Burden	+++	+++

Autism spectrum disorders

Dawba ID: Withheld
Details: Young Person

DSM-IV prediction: +
ICD-10 prediction: +

	Mother
Developmental level	
Concern in first 3 years about general mental development	++
General reasoning and school work at present	Advanced
Current mental age	
Serious concerns in the first 3 years	
about speech	++
about social interaction	++
about pretend play	++
about rituals / stereotypies	++
Continuing difficulties in any of these areas:	++
Social Aptitude Scale	10 VERY LOW
DSM 1a: markedly impaired nonverbal social interaction	
Abnormal eye contact at some age (too much, too little, wrong type)	++
Restricted use of nonverbal gestures as a toddler and young child	-
Finds it hard to read others' tone of voice and facial expressions	++
Others find it hard to read his tone of voice and facial expressions	+
DSM 1b: peer relationships not appropriate to developmental level	
Difficulty making friends	++
Difficulty keeping friends	++
Number of friends he fairly often spends time with:	0
Does not share interests with friends	
Does not do things jointly with friends	
Does not confide in friends	
DSM 1c: not spontaneous sharing enjoyment, interests or achievements	
Not sharing enjoyment, interests or achievements when aged about 4	-
DSM 1d: lack of social or emotional reciprocity	
Not enjoying simple social games as a toddler, e.g. peepo	++
Difficulty taking turns, sharing, cooperating	+
Fails to adjust play for older or younger children	+
Fails to adjust conversation for formal and informal situations	++

Autism spectrum disorders

Dawba ID: Withheld

Details: Young Person

DSM-IV prediction: +

ICD-10 prediction: +

DSM 2a: delay or lack of spoken language (without compensation)	
Concern about speech in first 3 years	++
No words before aged 2	-
No phrases before aged 3	-
Language expression and comprehension	Advanced
Current language age	
Poor at getting round language difficulties	
DSM 2b: (if adequate speech:) impaired conversation	
Bad at starting conversations with others	+
Bad at sustaining conversations started by others	+
Not interested in chatting about other people's interests	++
DSM 2c: stereotyped, repetitive or idiosyncratic language	
A lot of echoing (ever)	+
Repetitive questioning (ever)	++
Repetitive clichés (ever)	++
DSM 2d: impoverished pretend play (for mental age)	
Not regularly taking part in imaginative play (ever)	++
DSM 3a: intense or odd preoccupations	
Any 'obsessions'?	++
Unusual topic	+
Dominating his life	-
Dominating his conversation	++
Interfering with getting on with other things	+
DSM 3b: inflexible routines or rituals	
Repetitive play, e.g. turning light switches on and off (ever)	++
Strong or unusual routines (ever)	++
Very upset by change in routine (ever)	++
DSM 3c: stereotyped/repetitive motor mannerisms	
A lot of flapping (ever)	-
DSM 3d: persistent preoccupation with parts of objects	
Very interested in unusual aspects of toys and other things (ever)	+

Dawba ID: Withheld | DSM-IV prediction: +

Details: Young Person | ICD-10 prediction: +

Impact

Parental concern about language, play, flexibility etc	+
Distress	+++
Impact on family life	++
Impact on friendships	+++
Impact on learning	+++
Impact on leisure	+++
Burden	++

Timing of onset

Always there or sudden onset (with regression)?	Always there
Age when change took place:	

>> Open-ended comments: Mother

Concerns about earlier development
at nursery they flagged concerns of yp being able to pronounce some words, in reflection and although he still says yp's a bit different, his language was more elaborate for his years, he could us it in the right content but they were big words, this continues to date and his speech and ability to communicate is good. he never really sat and done pretend play he would more likely to be bouncing about or climbing, even if watching a film at home he will stand behind you and bounce. he used to walk on his tip toes and to an extent still does. his ability for sports was also above average for his age and therefore created even less fear of any dangers.

Current concerns
he would prefer to stay home to avoid any transitions or change

Description of 'obsessions'
yp has rocked since very young he continues to rock, yp also had a particular interest in the human body and how the earth moves/gravity, these were topics we had to listen to at length, he will now say I know you're not interested but I need to tell you.

Description of rituals
yp likes the same bowl for his cereal in the morning, he has to have the same seat in the car because he has identified it as the safest seat in the car, he has his seat if we are having a movie night and he only likes a particular brand of popcorn. yp could always tell if I swapped his usual brand of cereal for another. he had a timetable of his daily routine, we removed the time as this could cause distress if it didn't happen on time, this helped him be more self-sufficient in places like a shower where he would forget what the routine was.

Previous label? Who gave it?
he was diagnosed Asperger's at the age of 8, it was suggested then that he wasn't ADHD as he could behave in school, this wasn't the case he merely masked these difficulties, he has no formal diagnosis of ADHD, however, that is the reason he has been prescribed methylphenadate

Any help?
he has been prescribed methylphenidate and sertraline, he has taken a break under the psychiatrists supervision as he says it makes him feel numb.

Behaviors linked to developmental disabilities

Dawba ID: Withheld

Details: Young Person YP

	Mother
Stereotypic actions	
Rocking back and forth	++
Head nodding	++
Flapping or hand twisting	-
Fluttering fingers in front of face	-
Waving an object in front of face	-
Picking at skin	-
Head banging	-
Biting lips, hands etc.	-
Eye poking	-
Other repetitive actions	-
Age of onset of repetitive activities	0
Time spent on repetitive activities	+++
Impact	
Distress	+
Impact on family life	+
Impact on friendships	-
Impact on learning	++
Impact on leisure	-
Burden	+
Other issues	
Rough behaviour	+
Attacks others	-
Reduced sexual inhibition	-
Underactivity	-
Too noisy	+

>> Open-ended comments: Mother

Description of the problem

yp has always rocked, he is comfortable doing this at home but finds it hard to not do in public, he find that part distressing.

Interfering with quality of life?

he can find it embarrassing if people stare.

Resultant injury?
no

Trigger?
over excited, change in routine, change in what was expected to happen, leaving home.

Done anything about it?
try to stick to routine as much as possible.

Attachment Figures

Dawba ID: Withheld

Details: Young Person YP

	Mother	Self
Attached to:		
Mother	++	++
Father	-	-
Other mother figure	-	-
Other father figure	-	-
Grandparents	++	++
Adult relatives	++	++
Childminder, nanny, au pair	-	-
Teachers	-	-
Adult non-relatives	-	-
Brother, sisters		
Friends		

Separation Anxiety

Dawba ID: Withheld

Details: Young Person YP

DSM-IV prediction: - -

ICD-10 prediction: -/+

AF=attachment figure	Mother	Self
Any concerns about separations?	Yes	No
Loss of, or harm to, AFs	+	-
Being taken away from AFs	-	-
Not wanting to go to school	-	-
Afraid of sleeping alone	-	-
Sleeps with or checks on AFs at night	-	-
Afraid of sleeping in a strange place	-	-
Afraid of being in a room alone		
Afraid of being at home alone	-	-
Nightmares of separation	-	-
Somatic symptoms linked to separations	++	-
Anticipatory anxiety of separations	-	-
Symptoms for at least 1 month	++	
Age of onset	?	
Distress	+++	
Impact on family life	+++	
Impact on friendships	+	
Impact on learning	+++	
Impact on leisure	+++	
Burden	+++	

>> Open-ended comments: Mother

Description of the problem
yp mostly worries about his aging grandparents, yp struggles to understand death and this becomes a fixation, I need to let him know if I'm going out and not leave without him knowing this

How often?
it depends on how he is feeling but can be daily, escalates if his grandparents are particularly ill he won't sleep and becomes increasingly agitated.

First started?
since early years

Interfering with quality of life?
when we can communicate and find the source of the worry it can help, at worst prevents him leaving the house

Cause of worries?
The worries became more significant when his great gran past away.

Done anything about it?
we talk and have strategies to try help.

Social Phobia

Dawba ID: Withheld

Details: Young Person YP

DSM-IV prediction: ++

ICD-10 prediction: ++

	Mother	Self
Any concerns?	Yes	Yes
Anxious about:		
Meeting new people	++	-
Meeting a lot of people	++	-
Eating in front of others	++	-
Speaking in class	-	-
Reading aloud in front of others	-	-
Writing in front of others	-	-
Separation or social anxiety?	Social	
Frightened with adults/kids	Adults and kids	
Can socialise with familiar people	++	
Due to fear of embarrassment	+	
Due to delay in speech, writing, reading		
Age of onset	?	
Duration in months	6+	
Blushes in social situations		
Feels sick in social situations		
Urgency in social situations		
Upset when social fear is triggered	++	
How often social fear is triggered	Most days	
Avoids relevant social situations	++	
Avoidance interferes with daily life	++	
Child thinks fear is excessive	++	
Child upset to have social fears	++	
Burden	+++	

>> Open-ended comments: Mother

Description of the problem
yp is not good at reading social ques and facial expression, he is a logical thinker and doesn't have patience for small talk. in his words people just annoy him. if he is not interested in a subject he doesn't see the point in taking part.

How often?
yp has been in his bedroom for over a year, he very rarely wants to come out of it.

How severe?
he is isolated, bad days yp doesn't even want any of his family whom live in the house to be near him, he just sees this as a disturbance and annoying.

Social Phobia

Dawba ID: Withheld

Details: Young Person YP

DSM-IV prediction: ++

ICD-10 prediction: ++

Interfering with quality of life?
yes, he has lost all his strategies that enabled him to be self-sufficient.

Done anything about it?
yes, on a good day for yp I will sit and ask him about his computer game and ask about this interest as it is the only one he has just now, I need to enter his world as ours seems to challenging for him.

Panic Attacks and Agoraphobia

Dawba ID: Withheld

Details: Young Person YP

DSM-IV prediction: ++

ICD-10 prediction: ++

	Mother	Self
Panic attacks in last 4 weeks	++	++
Panics start suddenly		++
Peak within a few minutes		++
Last a few minutes		++
Heart races		++
Sweaty		++
Trembly / shaky		++
Dry mouth		++
Short of breath		++
Choking		-
Chest pain		++
Nausea / stomach churning		++
Dizzy / feeling faint		++
Derealization / depersonalization		++
Fear of losing control, going crazy		-
Fear of dying		-
Hot or cold all over		-
Numbness or tingling		-
Fear or avoidance of:		
Crowds	++	++
Public Places	++	++
Travelling alone	++	++
Being far from home	++	-
Fear or avoidance is due to panic attacks	++	-
Distress		+
Impact on family life		+++
Impact on friendships		+++
Impact on learning		+++
Impact on leisure		+++
Burden		+++

>> Open-ended comments: Mother

Panic Attack

this occurs when yp has to go out of his home, or if anyone comes to visit, this is out with his familiar surroundings, he can become very agitated, has difficulty breathing and can also become argumentative or causing barriers that will prolong attending events in the hope they need to be cancelled.

Fear/Avoidance

Panic Attacks and Agoraphobia

Dawba ID: Withheld | DSM-IV prediction: ++

Details: Young Person YP | ICD-10 prediction: ++

YP cannot travel independently, crowds overwhelm him and there are too many transitions for him to remember, he feels safest at home and his only outside of home interaction is with people he hasn't met in person that he games with, he has created a network of people through this, when younger he would often soil himself in these stressful situations. YP used to be very actively sporty now he wants home as soon as we are out and continually ask how much longer, despite times and the daily plan being given as much as possibly known.

>> Open-ended comments: Self

Description of panic attacks
feels as though my body is shutting down

How often panic attacks occur
very rarely

Panic attacks first began
4 years ago

Description of fear/avoidance
i stay at home because people get on my nerves

How often fear/avoidance occurs
everyday

Fear/avoidance first began
10 years ago

Interfering with quality of life?
it's made me less physically fit and more isolated

Done anything about it?
numb my emotions, made a big difference

Post-Traumatic Stress Disorder

Dawba ID: Withheld

Details: Young Person YP

DSM-IV prediction: +

ICD-10 prediction: +

	Mother	Self
Exceptionally stressful event	++	-
Serious accident	-	
Fire	-	
Other disasters	-	
Attack or threat	-	
Physical abuse	++	
Sexual abuse	-	
Rape	-	
Witnessed domestic violence	++	
Witnessed attack	-	
Witnessed accident, sudden death	-	
Other severe trauma	-	
Distress/behaviour change at time	++	
Present impact	++	
Flashbacks	+	
Nightmares	+	
Distress if reminded	+	
Avoids thinking or talking about trauma	-	
Avoids associated activities, places or people	+	
Blocked out memories	-	
Lost interest in activities	++	
Feels cut off from others	++	
Reduced affective range	+	
Loss of confidence in future	+	
Insomnia	++	
Irritable/angry	++	
Poor concentration	++	
Alert to danger	+	
Easily startled	-	
Symptoms began (months after trauma)	0-5	
Duration of symptoms (months)	3+	
Distress	++	
Impact on family life	+	
Impact on friendships	++	
Impact on learning	-	
Impact on leisure	-	
Burden	+	

Dawba ID: Withheld DSM-IV prediction: +

Details: Young Person YP ICD-10 prediction: +

>> Open-ended comments: Mother

Description of the severe stress
Yp still has a very explicate recollection of events and places when we lived with his father, r was always an over active child and he was often the target of his father's frustrations, this was when I had left the family home and r's father seen yp's behaviors as non-compliant, he wouldn't tolerate. R was often physically disciplined for this.

Consequences of the stress
yp has very little trust in people, on the opposite side of his sister, people need to prove themselves to him before ant trust can be achieved, r had recurring nightmares for many years relating to his father and often situations, smells and unpredictable behaviour would make him more anxious.

How often?
Yp now has a good understanding of his triggers, he is hyper sensitive to smells and textures, therefore sometime difficult to distinguish which is triggering him. he was recently prescribed melatonin , however, his nightmares came back so he didn't continue with this.

How severe?
symptoms are far less severe than several years ago, he previously would also soil himself if something triggered him especially with smells that reminded him of times with his father.

Interfering with quality of life?
not so much now, apart from his lack of trust in people.

Done anything about it?
yes we communicate a lot he always knows it is a safe place to talk if something is on his mind.

Obsessive Compulsive Disorder

Dawba ID: Withheld

Details: Young Person YP

DSM-IV prediction:

ICD-10 prediction: +

+

	Mother	Self
Any concerns?	Yes	Yes
Excessive washing	-	-
Avoidance of contamination	-	+
Checking	-	-
Repetitive actions	++	+
Touching things or people	-	-
Ordering / symmetry	+	++
Counting / avoiding unlucky numbers	+	-
Concern about contamination	-	-
Concern about bad things happening	-	-
Due to separation anxiety?		
Present daily for 2 weeks	++	++
Rituals or obsessions >1 hour per day	-	++
Insight that it's excessive	+	+
Reaction to rituals or obsessions	Neutral	Neutral
Resistance	+	++
Distress	-	-
Impact on family life	+	+++
Impact on friendships	-	-
Impact on learning	++	-
Impact on leisure	+	+++
Burden	+	+++

>> Open-ended comments: Mother

Description of the problem
yp has to have the same daily routine, when in car the radio has to be on an even volume number, yp would call most of his rituals his interests, he particularly likes forensics and looks into this in great detail, when covid 19 started he looked into the science and biology of this, he obsesses about facts.

How often?
these can be a challenge when he has so much information on a subject such as covid he will do what he can to avoid it.

How severe?
since covid and because of a health condition, this triggered yp's reluctance to go out of the house.

First started?
severely since 1st lockdown, yp was happy to not have to go to school and stay safe at home.

Interfering with quality of life?
yes

Done anything about it?
he has had input from CAHMS and school implemented a reduced timetable, but was still unable to attend school.

>> Open-ended comments: Self

Description of the problem
games

How often?
causes difficulties daily

How severe?
12-14 hours a day

First started?
3-4 months

Interfering with quality of life?
inside a lot more

Depression

Dawba ID: Withheld

Details: Young Person YP

DSM-IV prediction: +++

ICD-10 prediction: +++

	Mother	Self
Sad	++	++
Miserable daily	++	++
Miserable most of day	++	++
Can be cheered up	No	Briefly
Duration (weeks)	2+	2+
Irritable	++	-
Irritable daily	++	
Irritable most of day	++	
Improved by friends	Briefly	
Duration (weeks)	2+	
Loss of interest	++	++
No interest daily	++	++
No interest for most of the day	++	++
Duration (weeks)	2+	2+
Coincided with irritability/misery	++	++
Associated Features:		
Tired/no energy	++	++
Changed appetite	++	++
Weight loss/gain	++	-
Insomnia	++	++
Hypersomnia	-	-
Agitation	++	++
Feels worthless, guilty	-	-
Poor concentration	++	-
Thoughts of death	++	++
Recent talk of DSH	++	++
DSH recently	++	++
DSH ever	++	++
Distress	+++	+
Impact on family life	++	+++
Impact on friendships	++	-
Impact on learning	+++	+++
Impact on leisure	+++	+++
Burden	+++	+++

>> Open-ended comments: Mother

Description of the problem

yp is in a consistent low mood, he has very little interest in anything.

What else has changed?

Depression

Dawba ID: Withheld | DSM-IV prediction: +++

Details: Young Person YP | ICD-10 prediction: +++

yp has never slept well since birth, his appetite is less than before and wouldn't eat if it is not organized for him, he has very little motivation and is hard on himself if he doesn't manage to complete small tasks. he self-harms and has taken an intentional overdose of insulin in September 2021.

How often?
most of the time.

How severe?
he has expressed his need for self-harm, he had been using his needles to do this, he doesn't have access to this anymore as his mood is low and so to avoid any more attempts at his life with insulin.

When did it begin?
a few years ago.

Trigger?
when he was diagnosed type 1 diabetic. he doesn't want to live with it, the unpredictable pattern is something he finds hard to accept, especially as math's is a favorite of his, so in his mind if he counts his intake right it should all be fine, this isn't the case and he cannot accept this.

Similar episodes in the past?
no, he has always been anxious in new settings and asked the purpose of life and how we get here, but not in the way of he has no purpose and sees no point until a few years ago.

Ever gone 'high'?
no

Interfering with quality of life?
yes

Done anything about it?
yp attends psychiatry and has been prescribed medication, he is currently taking a break from this as he has stated it makes him feel numb.

>> Open-ended comments: Self

Description of the problem
very deep depression

What else has changed?
less appetite, didnt sleep, wanted to die

How often?
all of it

How severe?
not a threat but very severe

When did it begin?
3-4 years ago

Trigger?
no clue

Interfering with quality of life?
isolated from the outside world

Done anything about it?

Depression

Dawba ID: Withheld

Details: Young Person YP

DSM-IV prediction: +++

ICD-10 prediction: +++

no

Disruptive mood dysregulation disorder

Dawba ID: Withheld

Details: Young Person YP

	Mother	Self
Temper outbursts		
Frequency of outbursts	++	++
His temper outbursts involve:		
Slamming doors	+	-
Shouting	++	++
Swearing	++	++
Saying mean things to others	++	++
Saying negative things about himself	+	-
Physical aggression to others	-	-
Deliberate self-harm	++	++
Breaking things	+	-
His temper outbursts occur:		
At home	++	++
In the classroom	-	-
With peers	-	++
Longest outburst-free gap in the last year	< month	< week
His outbursts are easily triggered	++	++
His outbursts have recognizable triggers	++	++
Angry/Irritable mood		
Frequency of irritable/angry mood	+++	+++
Easily irritated	++	++
Intense irritability	++	++
Long duration of irritability	++	+++
Irritability evident to others	++	+++
His irritability occurs:		
At home	++	++
In the classroom	+	-
With peers	+	++
Age of onset	?	0
Angry weeks occur	Yes	Yes
(irritable most of the day, nearly every day)		
Proportion of angry weeks (past year)	Half	All
Longest gap between angry weeks (past year)	< month	< month

Disruptive mood dysregulation disorder

Dawba ID: Withheld

Details: Young Person YP

Distress	++	-
Impact on family life	++	+++
Impact on friendships	+	-
Impact on learning	+	-
Impact on leisure	+	-
Burden	++	+++

>> Open-ended comments: Mother

Description of the problem
temper outburst tend to happen less often than before, and mainly around the computer. there is computer games that trigger these outburst although directed at the game, the shouting can be stressful to the rest of us in the house. the outburst used to be when having to go to school, however he has not attended school this year due to lack of motivation and the anxiety and distress the school environment brings.

Trigger?
the main outburst is when r is being asked to come off the computer at night for everyone to be able to go to bed, or if he feels there is no reason or logic to what is being asked of him, he doesn't respond well to what he perceives as demands. he can become verbally aggressive, he also doesn't like reminding that he has to take his insulin which he states he can take himself, however he forgets very quickly and this doesn't happen, he then has an outburst when reminded to take it again

How often?
we have strategies to help work around these, however, the bedtime getting off the computer can still cause problems 1 - 3 times a week.

How severe?
he will shout, scream, and slam doors, he has little recollection afterwards.

Interfering with quality of life?
they can as it takes a process to try avoid these triggers that he finds difficult, there is not always time to do this, it also can cause distress to both his siblings.

Done anything about it?
yes we have worked on what causes distress and we work with an anxiety curve, this allows him to state what number he is at and we have an agreement and what should happen at these stages.

>> Open-ended comments: Self

Trigger?
people trigger my temper

Unstable and elevated mood

Dawba ID: Withheld

Details: Young Person YP

	Mother	Self
Unstable mood	+	++
Rapid	++	++
Marked	++	++
Unpredictable	-	++
Frequent	++	++
Duration	Hours	Hours
Elevated mood	+	-
Cheerful	+	
Talking fast	++	
Active	++	
Achieving more	++	
Noisy	++	
Spends money fast	-	
Needs less sleep	++	
Restless	++	
Over-sexed	-	
Frequent changes of plan	-	
Full of energy	++	
Talks to strangers	+	
Excitable	+	
Less concerned about trouble	+	
Invades personal space	++	
Over-confident	+	
Takes serious risks	++	
Jokes and laughs more	+	
More outgoing	+	
Irritable	+	
Distractible	+	
Disinhibited	++	
Poor concentration	++	
Too bossy	-	
Appearance neglected	++	
Rapid shifts of topic	+	
Visual hallucinations	-	
Auditory hallucinations	-	
Special powers	-	
Regret afterwards	++	

Unstable and elevated mood

Dawba ID: Withheld

Details: Young Person YP

Length of episode	< day	
Mixed affective state	++	
High in the last 4 weeks	-	
Longest episode in the last 4 weeks		
Impact on family life	++	
Impact on friendships	++	
Impact on learning	+++	
Impact on leisure	++	
Burden	+	

>> Open-ended comments: Mother

Description of the problem
yp had a belief that he had superpowers as a child up until around 9 yrs old, he has an ability to climbing things that should have been out with his ability at certain ages, such as stair gates he could climb over at the age of 11 month and climbed out his cot just coming up on 10months old. when he is particularly excited about something he has absolutely no danger awareness and restraining him can be difficult. he speaks over everyone if he finds his topic exciting or interesting and has no awareness that people are less interested about it.

How often?
only when something is exciting to him, with such a low mood recently these have been very little.

Shortest and longest episodes ever
the episode would last until he had exhausted the thing he found interesting or had attended or completed the thing he found exciting and had wanted to do.

How severe?
tree climbing was a problem he would go to the top without a thought, over talking could also be annoying to others.

First started?
from birth

Interfering with quality of life?
not so much now, this is because he feels low and has very little outside interruptions.

Attention and Activity

Dawba ID: Withheld

Details: Young Person YP

DSM-IV prediction: ++

ICD-10 prediction: +

	Mother	Self
Any concerns?	Yes	
Activity:		
Fidgets	++	
Can't remain seated	++	
Runs or climbs when shouldn't	++	
Can't play quietly	++	
Can't calm down	++	
Impulsiveness:		
Blurts out answers	++	
Can't wait for a turn	++	
Butts into conversations or games	+	
Unstoppable talk	++	
Attention:		
Time on task in mins		
Careless mistakes/inattentive	+	
Loses interest	+	
Doesn't listen	+	
Doesn't finish task	+	
Poor self organisation	++	
Avoids tasks needing thought	++	
Loses things	++	
Distractible	++	
Forgetful	++	
Teacher complains of overactivity	++	
Teacher complains of poor attention	++	
Teacher complains of impulsivity	+	
Child says parents complain		++
Child says teachers complain		++
Child thinks self hyperactive		+
Present for at least 6 months	++	
Age of onset	?	
Distress	++	
Impact on family life	+	
Impact on friendships	+	
Impact on learning	+++	
Impact on leisure	++	
Burden	+	

Dawba ID: Withheld | DSM-IV prediction: ++

Details: Young Person YP | ICD-10 prediction: +

>> Open-ended comments: Mother

Description of the problem
in younger years yp would climb on things and under things in supermarkets, in a park and soft paly he would climb on the outside of the equipment as it was more fun. he would try jump off of thing that were very high. now he prefers to avoid these environments and will more ask constantly when will I be finished and when can he go home. he constantly rocks on his gaming chair and can become very shouty , he uses a crossbar on his door to try help with his impulsiveness when he can't sit much longer.

How often?
more when we are outdoors because of dangers such as roads, he is out very little in the past year.

How severe?
he can just run off, often lost him when up at the top of trees. he cannot be consoled at sever points and need some sort of physical activity to help him level out.

First started?
since birth.

Interfering with quality of life?
when outdoor, constantly on alert of where he is.

Done anything about it?
when outdoors we go to more rural settings this help all three children relax a bit.

Substance use in last 4 weeks

Dawba ID: Withheld

Details: Young Person YP

	Self
Cigarettes	-
Number of cigarettes per day	
Strong need for cigarettes	
Wants to reduce cigarettes	
Alcohol	-
Consumed with friends	
Consumed with family	
Consumed alone	
Wants to reduce alcohol	
Annoyed by criticism of alcohol use	
Alcohol use interferes with life	
Strong need for alcohol	
Alcohol use leads to trouble	
Drugs	
Cannabis	-
Ecstasy	-
Solvents	-
Amphetamines	-
Tranquillisers	-
Cocaine	-
Crack	-
Opiates	-
Other drugs	-
Wants to reduce drugs	
Annoyed by cricism of drug use	
Drug use interferes with life	
Strong need for drugs	
Drug use leads to trouble	

Other concerns

Dawba ID: Withheld

Details: Young Person YP

	Mother	Self
Concerns in the first 3 years about:		
Speech		
Social interaction		
Rituals/stereotypes		
Cleared up or continuing?		
Tics		
Thin/dieting		
Abnormal perceptual experience		
Other concerns	++	-
Teacher has complained to parent of other concerns	++	

>> Open-ended comments: Mother

Other concerns
my concern is for yp's future, he has little motivation and any strategies we have created over the years he doesn't want to do, he used to be obsessive about his hockey and had other interests, now he can only manage being on the computer and hasn't managed to attend school for a year to enable him to do his national 6's which academically he could have achieved at least a year before he was to sit them, most importantly it is something he wants to do but is struggling to go outdoors, let alone school. i am concerned we can't get him to a level that he is able to manage his diabetes and stay on his own, and if he takes it upon himself to try suicide again.

Informant's account of teacher concerns
his nonattendance at school

Strengths

Dawba ID: Withheld

Details: Young Person YP

	Mother	Self
Qualities:		
Generous	-	+
Lively	-	
Keen to learn	++	
Affectionate	++	
Reliable and responsible	-	+
Easygoing	-	-
Good fun, good sense of humour	++	+
Interested in many things	++	
Caring, kind-hearted	++	+
Bounces back quickly after setbacks	-	
Grateful, appreciative	+	
Independent	-	+
Outgoing, sociable		-
Nice personality		++
Behaviours:		
Helps around the home	-	-
Gets on well with the rest of the family	+	
Does homework without reminding	-	
Creative activities	-	
Good at music		+
Good with computers		++
Good at drama, acting		-
Good at art, making things		-
Likes to be involved in family activities	-	
Takes care of appearance	-	
Good at school work	-	++
Polite	+	++
Good at sport	++	++
Keeps bedroom tidy	-	
Good with friends	+	+
Well behaved	+	+
Raising money for charity, helping others		-

>> **Open-ended comments: Mother**

yp is a caring boy who can become easily overwhelmed, he is insightful in peoples personalities and seems to not become involved in pettiness. he saves hugs only for the people most important to him and doesn't sugar coat things therefore you know exactly where you stand. he is good at advice as his attention to detail is great and he sticks to facts.

Interviewer's Comments

Dawba ID: Withheld

Details: Young Person

Interviewer of Parent1:
we have done a lot of work with r, we have many discussions on best ways forward therefore felt confident in answering the questions, there are many parallels in r's thoughts and behaviours so I may have went over things more than once.

Interviewer's Comments - 1 Created on: 08/07/2022 10:45

Appendix ii

Ethics and Process

In respect of this pilot, we recognise - The United Nations Conventions of the Rights of the Child, ratified in the UK in 1991, came into force in 1992, which has a degree of more legal effect in the UK's legal system through the Human Right Act 1998, we have made a conscious decision to ensure that this project is consent driven.

Critical to any piece of assessment work are ethic and processes. As a baseline, we took a typical university research study ethics form and identified the areas of concern that required addressing to ensure safety and protection of participants, family and their questionnaire supporters within this pilot project.

We concluded there are five key partnerships we need to consider and ensure we eliminate or reduce associated risks to an acceptable standard. The key partners were the local authority, health and social care partnership, the assessment tool owners and our charity partners, participants and their families.

After several months of discussions there was finally agreement on the following principles.

a) Consent Driven by either individual, parent carers or legal guardians or jointly in the interests of inclusion.
b) Anonymity in respect of data published and shared. Obvious exception is the consent form which we do not share anyway.
   We only share the Dawba Report and Advocacy Response with who we are authorised as per consent form.
c) Data Storage – Stored securely under multiple access security protocols. Consent forms are stored separately under different security to reports, advocacy response and participant overview. Reporting data is stored separately under different security again.
   Only data that will be kept beyond 3 months after report published will be the report. All else will be completely removed.
d) Protection Issues We have within the system a protection protocol if there become highlighted a risk of self - harm or harm to others.
   As per participant information leaflet and consent in this instance if this is a concern then we will kick-in the protocol.
e) It is up to individual, parent carers legal guardians and their partner agencies they interface with and practioner professionals they work with to identify next steps. Within the report and advocacy response are for information and considerations only.
f) No Harm nor false promises are made as part of pilot.
g) There would be oversight re DAWBA assessment after rating but before report issue by a clinical psychologist.
h) We would not issue or give a diagnosis as this is not part of the project.
i) Data would not be stored nor integrated via the pilot with local authority or NHS individualised records.

There are a couple of caveats

(i) Only exclusion which we cannot control is and again it is consent driven is who the individual/parent carer or legal guardian chose to self-direct the report or advocacy response after we have issued.

(ii) Case studies will be anonymised but there will be elements of self or family recognition by participant and their families. This is normal in respect of all case study work.

It was also agreed within pilot team at the offset the following disclaimer is issued with all reports/advocacy response -

Disclaimer - The above is based on the outcomes of the Development and Well Being Assessment and the Participant Overview. It has been issued for consideration and suggestion. It is up to the individual, subject to capacity, the parents/carers, legal guardians, in partnership with practitioners and professionals to decide and determine what actions are taken if any going forward.

Our process is duly set up to ensure this, over and above we built in an additional double layer of identify protection, between project coordinator and rater and again between rater and clinical psychologist, given an impact of reduction or elimination of the risk associated to unintentional professional bias.

As this is a small-scale pilot project, we designed a simple yet effective process that enabled us to meet the ethical needs. See diagram below.

Contact

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