

## Autism Strategy Review Group Approved Minutes

### OPEN MEETING

Thursday 12<sup>th</sup> March 2020

10.00am – 2.15pm

Inverclyde Academy, Greenock

**Present:** Gillian Barclay, Scottish Government; Lesley Evans (minutes), Autism Network Scotland (ANS); Anne Marie Gallagher, Greater Glasgow and Clyde National Health Service (GGC NHS); Rob Holland, National Autistic Society, Fiona Milne, Renfrewshire Carers Autism Spectrum Disorder Support Group; Annette Pyle, Scottish Government; Louise Scott, Scottish Government, Catherine Steedman, Autism Initiatives; Lynsey Stewart, Autism Network Scotland, Charlene Tait, Scottish Autism.

**Apologies:** Arron Ashton, Scottish Government; Kabie Brook, Autism Rights Group Highland (ARGH); Fiona Clarke, Parent representative; Sonny Hallett, Autistic Mutual Aid Society Edinburgh (AMASE); Richard Ibbotson, The Richmond Fellowship Scotland; Thom Kirkwood, Apex Associates; Prof Jean MacLellan, University of Strathclyde, Autism Network Scotland (ANS); Dr Janine Robinson, NHS Education for Scotland (NES); Stephanie Rose, Police Scotland; Dr Marion Rutherford, Queen Margaret University (NAIT); John Urquhart, COSLA; Nick Ward, National Autistic Society (NAS).

#### Welcome and Introductions

Michael McLennan (MMcL), Community Development & Engagement Officer, The Advisory Group (TAG) welcomed everyone to the event. He then introduced Allen Stevenson (AS), Head of Service for Health and Community Care, Inverclyde HSCP and Autism Lead for Inverclyde Council.

AS welcomed everyone and thanked the Autism Strategy Review Group for making the journey to Inverclyde. AS said he was delighted to showcase the good work in Inverclyde and is aware there is still more to do and that involves a need for better partnership working. AS thanked MMcL saying how invaluable TAG were. AS told the group an important council meeting was taking place today, discussing the proposed £7.5m community learning and disability hub which will keep Autism on the agenda, with the aim to help people thrive in Inverclyde. AS concluded by saying he hoped the Group would leave with a sense of what Inverclyde is currently doing, as well as a sense of ambition for what they want to do moving forward. AS introduced Gillian Barclay (GB).

#### Review Group Introductions

GB thanked AS and everyone for coming, saying members of the Review Group were delighted to be here.

With the 10 year national strategy moving into its final phase (finishing 2021), GB explained that the Group is trying to travel around the country to hear about challenges faced as well as good practice. GB introduced the Review Group members.

Having read the Inverclyde self-evaluation report, GB said some of the less positive issues highlighted are very common, e.g. training of staff in schools and health service is something Scottish Government (SGovt) knows needs to be addressed. GB said there is still more to do to ensure professionals know and understand that autism is not just an issue but has to be treated in a certain

way. **GB** also noted the importance of diagnosis and post diagnosis support, stating **SGovt** is trying hard to develop more coherent pathways across the country for children and adults. **GB** hoped there would be an opportunity to highlight what is happening nationally regarding specific topics throughout the day.

**MMcL** introduced **Loranda Guinea (LG)**, Nurse Team Lead and **Yvonne MacLeman (YMacl)**, ASD Team Lead, Specialist Children's Services NHS GG&C, Skylark Centre

### **Starting Out.....**

**LG** spoke about pre and post diagnostic support, highlighting referral criteria, the route to ASD assessment, the assessment process and post-diagnostic support.

### **Referral Criteria**

All children with any neurodevelopmental concern are referred via the Skylark Centre, which covers from birth to 19. There are 2 x pathways depending on the age of the child.

### **Children under 5 - Current waiting time for 29 children is approx. 26 weeks for an assessment.**

- Assessed by one of the nursing team
- If accepted and all universal services exhausted, Skylark see them for a Schedule of Growing Skills (an overall review of their development).
- Meet with a paediatrician to exclude any other underlying developmental condition
- Depending on their needs they are referred to other services before being added to the under 5 ASD waiting list.

### **Children over 5 - Targets are currently being met.**

- Referred into the Skylark Centre for an initial assessment with someone from the nursing team who tries to see them within 6 weeks.

### **The Route to ASD Assessment and Assessment Process**

- Referrals coming to the right place allows for some pre-diagnostic support (e.g. Physio, OT, Dietician) to be offered whilst waiting for other organisations.
- Referrals can come from any service (schools, GPs, paediatricians, SLTs, CAMHS). Skylark tend not to accept parental referrals unless they are already known to the service.
- All children progressing to an ASD assessment will be seen.
- Due to the size of the waiting list, questionnaires are now sent out to parents and schools for the diagnostic team to use alongside ADOS.

**YMacl** advised a process mapping exercise is underway to review the process due to the importance of getting it right.

**LG** discussed data collated up to February 2020, noting the school age population is the biggest pressure point and stated that **YMacl's** post was created due to pressures with school age children and the need to try and streamline diagnosis.

The data highlighted:

- more boys referred to the service than girls, which was quite common
- more 5-11 year olds

- total wait for first appointments was approx. 83 weeks in December 2019. The waiting time has been reduced to 61 weeks with the introduction of additional sessions, which will be seen in the April data.

**YMaCL** said that in clinical terms, they have one full time equivalent member of staff to do autism assessments for 105 children on the waiting list.

### **Post Diagnostic Support**

Every child with a positive diagnosis of ASD is invited to a post diagnostic support session, which also offers additional support to parents.

- Anyone with ongoing health needs is still seen within the Skylark Centre, to ensure regular disability reviews.
- Parents can return if they have any concerns about children with no underlying health condition(s).
- Children who have been discharged due to a lack of need for any ongoing support often return when they hit transitions stage.

In terms of post diagnostic support Kirsty Fowler, Masters in Autism, has recently joined the team.

The team is keen to benchmark “customer satisfaction”, looking at where they are currently, how satisfied those who have used the autism assessment service are with the process; what they would like to change, like to add, and what they would like to lose. Also under consideration is the waiting list and the teams’ own learning and development plan. They are very committed to working with their partner agencies.

**MMcL** thanked **LG** and **YMaCL** before showing a video interview with **Laura Graham (LGr)**, parent and founder of Kerr’s Journey. The video highlighted **LGr’s** lived experience with Kerr, her autistic son. **LGr** described her emotional journey through Kerr’s diagnosis and the reasons that led to her setting up Kerr’s Journey (blog). The blog went viral as she reached people in a similar position and this peer to peer support opened up a new world. **LGr** is now helping others via the support group housed at the Community Centre.

Table discussion groups followed.

### **Discussion feedback from the tables included:**

- Diagnosis is just the first step, follow up is essential; parental experiences of the assessment process are varied; diagnosis provides answers that parents were already aware of; important that diagnosis listens to and trusts the parents’ experiences
- What is available for families in crisis? There is a need for more family therapy
- Need to educate society from an early stage i.e nursery to encourage acceptance and understanding; also need a culture where professionals can say they don’t understand or have the necessary knowledge or skills; Need to have back up if education, health packages fail – is there a training need?
- Fantastic that data is being gathered to measure impact

Inverclyde HSCP will collate the comments to be shared.

## **Q & A from topics discussed at tables included:**

**Q: If there is only one full time equivalent in YMaCL's team, is that about funding?**

A: Ultimately, yes, there's a finite source for funding.

**Q: What support provisions are being put in place for parents?; How do we know about Kerr's Journey and how do we spread the word?**

A: Following diagnosis parents are signposted to Inverclyde Carers Centre; there is also a reliance on other parents sharing information. Part of the priority work of the strategy is putting together pre and post diagnosis information packs. Kirsty Fowler is leading on the post diagnostic path with John Chapman.

Kerr's Journey can be accessed via social media which continues to spread the word.

**Q: What happens if a child is not given a diagnosis but additional needs continue and the children and families access support?**

A: They are referred to Inverclyde Communication Outreach Service (ICOS) and it depends on what additional support needs are. Every child will have GIRFEC plan.

**MMcL** then introduced **Jan Spence (JS)**, Principal Teacher, Inverclyde Communication Outreach Service (ICOS).

### **Growing Up.....**

**JS** discussed support in school, stating that the ICOS package looks different for every child in Inverclyde thanks to GIRFEC. The service is not diagnostic dependent. They take children who have a communication difficulty.

There are 3 team areas:

- Early Years – Transition into primary school, up to end of P3.
- Primary outreach – Transition from primary to secondary school, s1 to end of s1. If needs extend beyond s1, **JS** ensures continuity by treating them as secondary outreach.
- Secondary outreach – Transitions from secondary to adulthood. Work with pupils in secondary school, their community and Return to School programmes. Many find it a real struggle. Home tutoring is available for those unable to come into school.

Work in Port Glasgow, Greenock and Gourock with 339 young people and children making up their current caseload. Numbers have been bolstered by the transitions group with 60 young people highlighted as needing help transitioning into Secondary school. Numbers dip slightly in Secondary which may be due to college placements, who they don't work with.

**JS** described ICOS as providing:

- Working 1:1 with the child; Bespoke programmes for individuals
- Running Skills Groups; Running Transitions Groups
- Staff Training – skill group training, play training, communication training with schools across Inverclyde
- Awareness Raising in schools - peers and staff; Hosting Autism Friendly Network – all primary schools; Implementing Communication Friendly Schools Awards; Assisting Schools with their Autism Plans

- Holding staff drop in sessions – via early years, primary and secondary
- Facilitating parent groups in all educational establishments – not as successful as they thought they might have been, so looking at these again. Running another session on 17<sup>th</sup> March where parents from all the feeder schools have been invited.
- Running Parent training – Early Bird Plus trainers and Cygnet Trainers – can do bespoke programmes

ICOS is engaged in partnership working, working with health and social work, parents and school support staff.

**MMcL** thanked **JS** then introduced **Aiden Stuart (ASt)**, Pupil, Inverclyde Academy. **ASt** shared the following during a brief Q & A. **ASt** told the group he enjoyed hands on, practical activities such as cookery and woodwork. When asked what support at school is worthwhile for him, he replied “definitely Jan through secondary school and Mary Rogers at primary school”. Exams, stress and environment caused problems for **ASt** and to better support young people at school, **ASt** would like training for teachers so that they can understand the “analysis side of things and explain it in a way I can understand it, as I struggle with it”. **ASt** is undecided about what he would like to do on leaving school, but it will probably be something practical.

**MMcL** thanked **ASt**.

Table discussion groups followed. Inverclyde HSCP will collate the comments to be shared.

#### **Q & A from topics discussed at tables included:**

##### **Q: How can children be supported in exams?**

**A:** Remove “big” exams. There is the option to have a “safe person” within the room or examinee’s home, which is SQA approved.

##### **Q: Is there a place for online home schooling?**

**A:** Michael Roach is talking about a virtual school in Inverlyde which would use Moodle, giving access to college and university courses online.

#### **Moving On.....**

**MMcL** introduced **Heather Simpson (HS)**, Strategic Lead role for learning disability services and autism, and **Lorraine Harrison (LH)**, registered manager, Inverclyde HSCP learning disabilities day opportunities service and alternatives to talk about transitions.

**HS** discussed the “big transition” pilot project<sup>1</sup>.

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<sup>1</sup> This is the transition from school into adulthood. Development for the project began in February 2018 for a June transition, supporting 3 young men with autism and learning disability (quite complex needs). It also included 1 young man who transitioned the year before that Inverclyde hadn’t quite got it right for. Service was required 4 days per week. High staffing levels were required due to the risk management element around keeping the young people safe. There were no additional resources and it was a very late transition at that time.

The critical factors considered included:

- Short time frame
- High level of needs for the young men who were non-verbal, making sure they were involved in the process as much as possible; Specific communication needs
- Behavioural challenges – very high risk e.g. running away, attraction to machinery, various triggers
- Legal framework – capacity and self-directed support options (had to make sure right framework was in place to ensure that parents could take forward any kind of options (guardianship process)
- The environment in which to support the young people was so important to this particular project - needed to be in a safe environment, an outdoor space where they would be able to develop independent skills and be in control of their own environment
- Staff training and capacity due to the amount of work required; no additional resources

There was a need for a multi-disciplinary, co-ordinated approach between health, education, young people and their parents and partners Belville Community Garden, Parklea Branching Out, Community learning and development i-zone and social work. The priorities for the young people with learning disability and those with autism is employability; developing skills and having ongoing adult, lifelong learning type of focus). An inclusive, community based, outcome focussed support was important.

The Principles of Good Transitions <sup>3 2</sup> were considered, however, due to the short time frame, many of the Principles could not be implemented.

**LH** discussed the personal outcomes for the young people:

- Ensuring the right staff team was in place
- Outcome focussed support planning training provided by **TAG**
- Ensuring the outcomes for the young men were being met in a way that wasn't a traditional model of service.

**HS** advised the project is currently being evaluated, however, personal and strategic outcomes are being met locally and nationally around Keys to life, the Autism strategy, employability, health and social care outcomes etc. The project was cost efficient, reducing costs by approx. 28% due to a personal outcomes focussed approach, the risk management and economies of scale. It has allowed Inverclyde to look at areas of improvement in terms of training, communication tools, and risk management and learnings from this group will help, as **AS** mentioned earlier, the design of a new hub with outdoor spaces.

Transitions remain a priority area for Inverclyde and some of the autism fund will be invested locally to work with the Association for Real Change (ARC) for a year to look at all transitions processes.

**MMcL** thanked **HS** and **LH** before inviting **Sharon Gemmill (SG)**, Manager, Parklea Branching Out, **Laura Riley (LR)**, Manager, Belville Community Garden and **Donna Elder (DE)**, Parent to participate in a short Q&A with the panel.

First question directed to **SG** and **LR**

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<sup>2</sup> <https://scottishtransitions.org.uk/7-principles-of-good-transitions/>

**Q: What motivated you as organisations to get involved in a project like this?**

**A: SG** – Parklea has been in partnership with the HSCP for many years. We provide a service to young people and adults with learning disabilities, so it felt like a really good opportunity. As an organisation we wanted to help the young people develop their skills and use our model to help develop opportunities for young people that have autism.

**LR** - it was a brand new project for Bellville as we hadn't really worked in this area before. We were very aware that many of our staff had a natural skillset and ability, lived experience with autism, with children or themselves who are autistic, so we wanted to utilise that and to be able to push boundaries to try something different. We had a couple of young people who had come to us for work experience and we thought we can do more with this.

**Q: Can you tell us about things that have worked particularly well about this project and the opportunity**

**A: SG** for us it's being able to see the young men settle in. Although we had previous experience working with a local school being able to see the young people being part of a peer group and taking part in activities and developing their skills and communication and being accepted for who they are has been so important. Having these coping strategies, they are confident in a new environment and that they can adapt to that. **LR** agreed, it's watching the young people develop, finding out what they enjoy, what they don't enjoy, but it's also for us as staff being able to push those boundaries to try things that sometimes don't work.

**Q: DE, what impact has this had on your son?**

**A:** It worked well for us. My son is happy to go to Bellville and Parklea, whereas previously going out to school had been difficult. He enjoys being around others and is now seeking the company of new people to spend time with. His communication has "come on" and he's really trying hard to communicate – he is non-verbal, so we have a daily diary that we use. There were always regular meetings and any tweaks that needed to happen, happened very quickly. There were realistic and flexible targets with how we're working with the boys, and tailored activities.

**Q: For all three, on reflection, is there anything you'd do differently, now that you've had this experience?**

**A: SG**, as we move forward it keeps coming back to communication, not just for someone with additional support needs but for everybody. **LR**, it's always communication. At Bellville, we're more confident about talking to people who're autistic and also with our experiences, we've become more confidence in ourselves in what we can provide. We were quite timorous when we started and now we're quite proud of what we've been able to achieve. **DE**, I think ongoing staff training for everyone and starting a transition, much, much earlier. Autism doesn't stop when the young person leaves school and I think we need to remember that, that they still go on and live beyond 18 years old and families need the support too.

**MMcL** thanked the panel.

Table discussion groups followed.

**Q & A from topics discussed at tables included:**

**Q: How do you refer into the project?**

**A:** Still evaluating the best way to roll out

**Q: why was it a late transition?**

**A:** As far as we can tell processes were not being followed, and we didn't work together as well as we should have. Supported employment and work placements is a priority area and Inverclyde is looking for funding to develop this to cater for those who do not meet the eligibility criteria for standard support services.

**And Beyond.....**

**MMcL** introduced the **Bethel Family, Stephen Bethel, dad (SB), Aaron, son (AB) and Alison, mum (ALB)** to speak about moving on, their experiences with autism and adulthood.

**SB** said he knew little about Aspergers and although he had heard of autism, it was never a subject that was raised until **AB** was born in 2005 (**AB** was diagnosed with Aspergers at 4/5 years old through the Skylark Centre). Looking up the definition online, **SB** had a "light bulb moment" regarding his own life experiences. **SB** said that during his time at High School there did not appear to be any additional support or help available. If he had received help it may have helped at exam time from an academic point of view. **SB** said a formal diagnosis would not have made a difference to him at the age of 35 years.

**MMcL** asked **AB** if he saw any similarities between him and **SB**. **AB** replied that yes he does, they are both strong-willed and have similar likes and dislikes. When asked what support he gets that may have helped **SB** at his age, **AB** said additional support with lessons and clear explanations to help you keep up.

**ALB** was asked what support she received as a carer? **ALB** said although both **SB** and **AB** have Aspergers they're both completely different and everything they've put in place, they've worked hard to get. Over the years she has used a range of services including Mind Mosaic, the Carers Centre, CAMHS, Skylark, Child Enterprise and every experience with these services was great. There are good services out there, however, they don't seem to connect with one another, with many parents unaware what is available.

A fire alarm brought this section of the meeting to a premature end. Returning after the fire alarm, **MMcL** thanked the **Bethel Family** for their honesty.

Table discussion groups followed.

**Topic discussed: Transitions – Children to Adulthood**

**Key points:**

- Require social enterprise initiatives
- Training required for everyone,
- ASD awareness days in shops etc at decent times



### **Topic discussed: Training and Awareness Raising**

#### **Key points:**

- Communication between everyone is absolutely key; Everyone is doing really good work, but need to share it more
- Utilise knowledge, skills and experience of autistic adults to support and mentor younger, autistic people
- Need to think about what's available locally for adults and older adults not just Inverclyde wide but individual communities
- Quality assurance of autism training and more autistic involvement, including development and delivery of training; Three levels of training – informed, advanced, expert

### **Topic discussed: Pre Diagnostic Support heads off crisis management**

#### **Key Points**

- Post diagnostic support is important to access when the families need it rather than when professionals think they should need it
- Specific Community Development Team , rather than having Skylark Centre and CAMHS have a team that looks at ASD, ADHD, FASD

### **Topic discussed: Supports in Education**

#### **Key Points**

- ICOS support being an all-round support, family support
- Training for staff
- Better Communication – exams, transitions and work experience

### **Topic discussed: Transitions in later life**

#### **Key Points**

- Helping autistic people develop a better sense of their autistic self

**MMcL** thanked everyone and invited **GB** to make her closing remarks.

**GB** said it had been a really useful day, hearing from people with lived experience which is important to keep the Group informed of what's happening around the country. **GB** highlighted the following points that the Review Group would take away from the day:

- the way **LG** and **YMacL's** team are developing their Children's Diagnostic Pathway is impressive and **GB** is keen to hear the outcome of the test of change
- **LGr's** video describing her lived experience and accepting her child's diagnosis was really interesting and powerful and it was fascination hearing how the Bethel family cope
- ICOS is a fantastic service as it is very supportive and reactive. It is a model that **GB** would like to promote further
- **ASt** made **GB** think about exams. She hoped allowing people to sit their exams differently was happening across Scotland and will investigate further
- the transitions project sounded very positive, although why it was so late?
- communication between the different services seems to be a common issue

In conclusion, **GB** said there were some useful learnings to take from the table discussions and the event as a whole and that she hoped all the tests for change were successful. It is important that Inverclyde continue to involve autistic people in everything they are currently doing and in going forward. **GB** congratulated Inverclyde on their successes, acknowledging there will always be people missed, but that Inverclyde are going in the right direction.

**GB** thanked everyone on behalf of the Review Group.

**MMcL** closed the meeting by thanking the Autism Strategy Review Group Team for coming along, and all who contributed in terms of presentations and lived experiences on behalf of **AS**.

**Approved by SG**

