

## LILAC: An Integrated Approach to Diagnosis and Intervention in Autism Spectrum Disorder

C. Duff<sup>1</sup>, A. Lyons<sup>1,2</sup>, E. Bohan<sup>2</sup>, A. Mulvihill<sup>2</sup>, S. Ní Chadhain<sup>2</sup>, R. Howard<sup>2</sup>, O. Flanagan<sup>1,2</sup>

1. Department of Paediatrics, Galway University Hospital, Newcastle Rd., Co. Galway, Ireland.
2. Central Galway and Galway City East Community Disability Network Team 6, Newcastle Rd., Co. Galway, Ireland.

### Abstract

#### *Aim*

The study aimed to address the issue of long waiting times for formal Autism Spectrum Disorder (ASD) assessment and intervention in children referred to Community Disability Network Teams (CDNTs) in Ireland. CDNT 6 in Galway City East established LILAC, an integrated intervention and diagnostic process for ASD, as a pilot programme and waitlist initiative.

#### *Methods*

The pilot study recruited 16 pre-school children and was conducted over 12 weekly sessions, delivered through a family-centred approach. These sessions comprised parental education and activity-based interventions for children. A diagnostic report with specific intervention recommendations was provided to parents in a feedback session.

#### *Results*

Of the 16 children who participated in this pilot study, 14 received a diagnosis of ASD within 12 weeks. Thematic analysis and descriptive statistics from the staff survey indicate that LILAC is an effective and effective model of care, in alignment with the principles of Progressing Disability Services (PDS).

#### *Discussion*

The study demonstrates that LILAC provided a family-centred interdisciplinary approach to intervention and diagnosis of ASD. Further investigation of the benefits of LILAC is planned, including measurement of parental satisfaction.

## Introduction

Autism Spectrum Disorder (ASD) has become increasingly prevalent in the developed world over the past decade<sup>1</sup>. For instance, in Northern Ireland, the diagnosis of ASD among school-aged children has risen from 1.2% in 2009 to 5% in 2023<sup>2</sup>. Community Disability Network Teams (CDNTs) in Ireland have received a growing number of referrals for autism in children. Pre-school children are typically referred by General Practitioners, Area Medical Officers, and Public Health Nurses, reporting delays in communication and social interaction skills. This increase in referrals has created a significant diagnostic and intervention workload for CDNTs, exacerbating long waiting times for children and families to access community services.

From 2011 to 2021, the Central Galway and Galway City East Community Disability Network Team 6 (CDNT 6) received a 78% increase in query ASD referrals. This represented a much greater proportion of their total referrals, from 36% to 64%. These children typically waited up to 18 months for clinical review by the CDNT. Following this initial review, it could take a further 18 months for a formal ASD assessment. Only after receiving an ASD diagnosis, families finally received interventions from the CDNT. However, these treatments were delivered independently by healthcare professionals of a variety of disciplines. This yielded a fragmented approach to patient care.

To address this issue, CDNT 6 established LILAC, a pilot program for children newly referred to the CDNT with a query of ASD. LILAC was originally designed as a waiting list intervention for children awaiting ASD assessment. Over time, it evolved to incorporate diagnostics, when it became apparent that enough information was gathered and observed through LILAC to make a formal ASD assessment. LILAC aimed to reduce waiting times for patients and families by providing an integrated approach to assessment, intervention, and ASD diagnosis, if applicable.

LILAC was designed as a family-centric approach to care. Over twelve weekly sessions, it provided strategy- and activity-based interventions for children, while simultaneously delivering parental education. At the end of this process, families received a detailed diagnostic report and individualised recommendations for intervention. In partnership with the interdisciplinary team, parents were empowered with the skills and knowledge necessary to meet their child's complex needs.

## Methods

We conducted a pilot study to evaluate the feasibility and effectiveness of the LILAC intervention for pre-school children with suspected autism spectrum disorder (ASD). LILAC is an interdisciplinary programme that involves cognitive, behavioural, and social stimulation for children and parental support and education for families. The intervention team consisted of a community nurse, a psychologist, a physiotherapist, an occupational therapist, a pre-school liaison teacher, a social worker, and a speech and language therapist, who worked closely with two consultant paediatricians specialised in neurodevelopment and neurodisability.

We recruited two cohorts of 8 children each for a total of 16 children, aged between 2-4 years, who were referred for query ASD by their primary care providers between April 2021 and October 2022. The inclusion criteria were: (a) having developmental delays or difficulties in communication and social interaction, and (b) having no other diagnosed medical or genetic conditions that could explain the symptoms. The exclusion criteria were: (a) having a confirmed diagnosis of ASD or other neurodevelopmental disorders, and (b) receiving any other interventions or therapies for ASD during the study period.

LILAC is an acronym for Laughing, Interaction, Listening, Attention and Communication. It is an intervention programme that aims to improve the cognitive, social, and emotional outcomes of children with suspected ASD. The programme is based on various evidence-based strategies and methods, such as the Floortime approach<sup>3</sup>, positive behaviour support<sup>4</sup>, joint attention activities<sup>5</sup>, the TEACCH programme<sup>6</sup>, and the Hanen programme<sup>7</sup>.

Families received 12 weekly sessions of the intervention, each lasting 45 minutes, at a community-based centre. The first session was an initial assessment, where a multidisciplinary team member collected a detailed clinical history from the parents and conducted a comprehensive developmental evaluation of the child, focusing on the areas of communication and social interaction. The team member also assessed the level of clinical suspicion of ASD based on the available evidence and informed the parents about the study procedures and objectives. The parents were asked to sign a written consent form before enrolling their child in the study. The subsequent 11 sessions consisted of structured and semi-structured activities for the children, such as games, puzzles, and stories, that aimed to enhance their cognitive, language, and social skills. The parents were also involved in the sessions, receiving guidance and feedback from the team members on how to support their child's development and cope with the challenges of raising a child with suspected ASD.

During the sessions, the children are also assessed for ASD by a clinical psychologist, who observes them through a two-way mirror in a separate room. The psychologist utilised a play-based proforma, based on ADOS-type activities. Standardised assessment was performed using the CARS-2 diagnostic tool, which is suitable for structured activity-based assessment<sup>8</sup>. This enables the team to provide simultaneous intervention and diagnosis for children with query ASD. If a diagnosis remained unclear, an ADOS would then be performed<sup>9</sup>. The children were required to meet DSM-5 criteria to formally diagnose ASD.

As part of the 12-week programme, the parents attended weekly group sessions led by the team members, where they received education and support on ASD and related issues. At the end of the programme, the parents had individual meetings with the team representatives, who explained the CARS-2 and ADOS assessment tools and their results. Parents received a detailed diagnostic report, including tailored intervention recommendations based on their child's strengths and needs, and advice for choosing the optimal school setting. Each child was referred to a paediatric consultant and relevant members of the CDNT for outpatient follow-up, ensuring continuity of care. Furthermore, the provision of an ASD diagnosis enables children to access appropriate specialist services, including Access and Inclusion Model (AIM) pre-school supports, ASD-specific school placements, and Special Needs Assistants (SNAs).

The study employed a mixed methods research design, collecting both quantitative and qualitative data. After the programme delivery, the LILAC team members (n=5) filled out a questionnaire to evaluate the programme's feasibility and effectiveness. The questionnaire used a Likert scale with 12 items, ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). Descriptive statistics were calculated from the quantitative data.

Additionally, one-on-one interviews were conducted to collect qualitative data on the programme. The researchers posed open-ended questions to the team members to elicit their opinions and experiences of the pilot. The qualitative data were then subjected to thematic analysis<sup>10</sup>, examining three main themes: interdisciplinary teamwork, family-centred practice and child inclusion.

## Results

Out of the 16 children and families who took part in the LILAC pilot programme, 14 were diagnosed with ASD. The remaining two children were diagnosed with ADHD and mild intellectual disability, respectively, after undergoing formal ADHD assessment and cognitive testing. The thematic analysis of the qualitative data from the team members revealed positive feedback.

Their responses focused on three key themes: interdisciplinary teamwork, family-centred practice and child inclusion (Table 1).

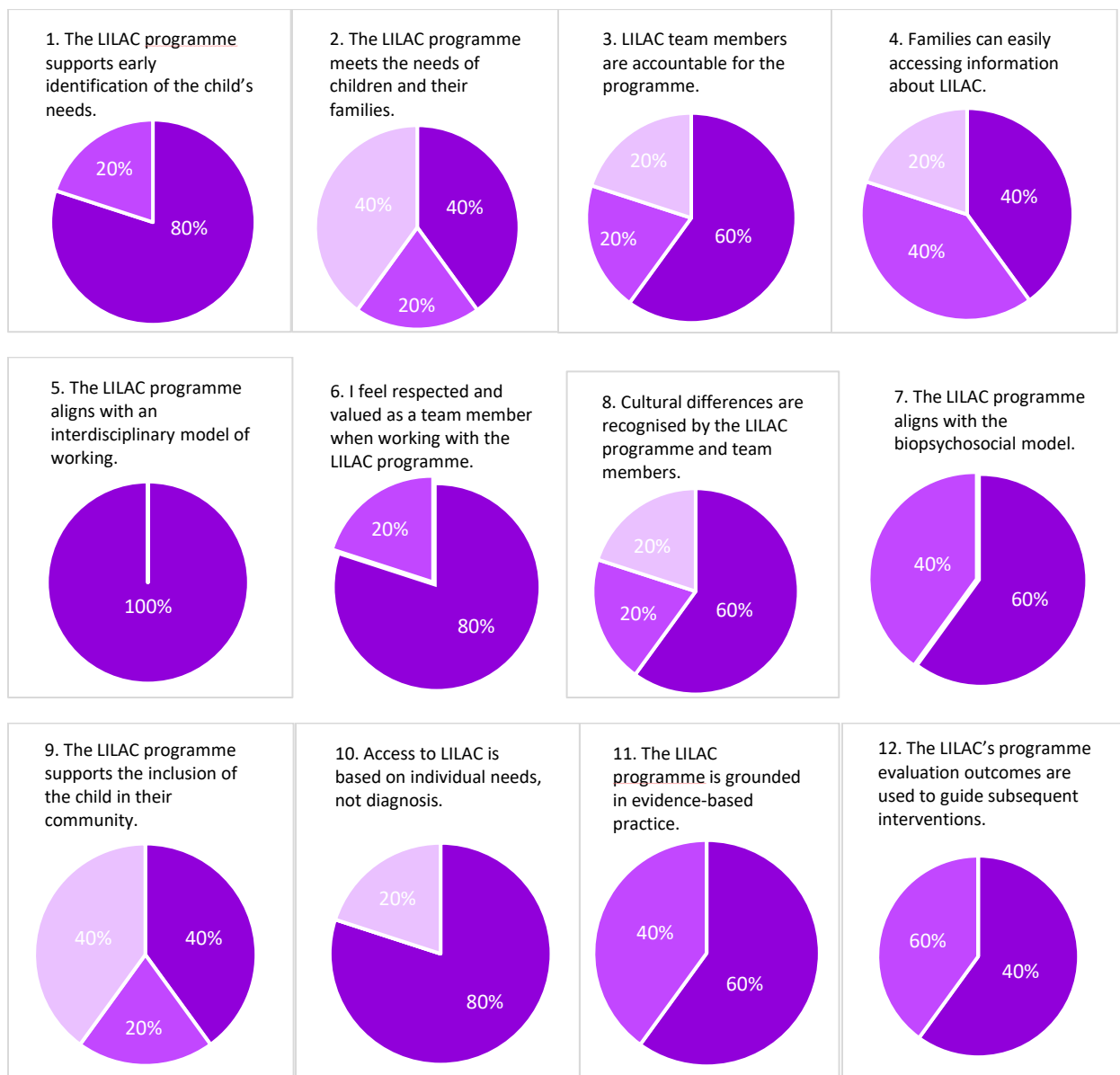
*Table 1: Thematic Analysis of Interdisciplinary Team Survey*

Theme	Feedback
Interdisciplinary Team Work	<p><i>“A highly effective and efficient mode of interdisciplinary service delivery.”</i></p> <p><i>“The programme appreciates all contributions from staff, with diverse backgrounds and expertise”.</i></p> <p><i>“Facilitates interdisciplinary collaboration”.</i></p> <p><i>“LILAC enables parents to perceive the team as an interdisciplinary unit from the beginning of their journey with us”.</i></p>
Family-Centred Practice	<p><i>“All interventions proposed are very customised to each child and family.”</i></p> <p><i>“Parents are assisted by staff, who demonstrate and coach throughout each session as needed.”</i></p> <p><i>“[Activity-based interventions] reveals to parents what their children could achieve, and what they had difficulty with”.</i></p>
Child Inclusion	<p><i>“The programme enhances the children’s participation in their local community through pre-school/play groups, by fostering their overall development, such as communication, social skills, play skills, and social interaction skills”.</i></p> <p><i>“Acquiring everyday skills will assist the children at home and prepare them for pre-school and school routines”.</i></p>

The quantitative data also showed a positive response to the LILAC programme. The descriptive statistics from the staff survey demonstrated the effectiveness of the study (Figure 1). The

questionnaire indicated that 100% of the team members (n=5) “strongly agreed” that “the LILAC programme conforms to an interdisciplinary model of working”. Similarly, 80% (n=4) of the staff strongly agreed with the statement that “the LILAC programme facilitates early identification of the child’s needs”.

*Figure 1: Staff survey in response to LILAC Study*



■ Strongly Agree   ■ Agree   ■ Neutral

## Discussion

LILAC exemplifies an interdisciplinary approach to the evaluation, diagnosis and treatment of ASD. The team members cooperate with two consultant paediatricians, who are also involved in the diagnostic process. This method is consistent with national and international best practice guidelines for paediatric ASD<sup>11</sup>. The programme conforms to the twelve principles of Progressing Disability Services (PDS)<sup>12</sup>. The staff survey indicates the study's adherence to these pillars of care; such as early identification of need, interdisciplinary team approach and family-centred practice. This is corroborated by the thematic analysis of the qualitative data, which corresponds to three pillars of PDS: an interdisciplinary team approach, family-centred practice, and child inclusion.

The outcomes of Goal-Based Interventions align with the Individual Family Service Plans (IFSP). Parents articulate the objective of investigating the reasons behind their child's communication challenges, such as the absence of speech. For example, many parents ask "Why isn't my child talking?". The prescribed intervention goals encompass universal early intervention methods that have demonstrated benefits for children with autism.

The interdisciplinary team intends to extend the LILAC programme to a larger group of children referred to the service with a query of ASD. The team expects that this comprehensive approach to assessment and intervention can be adopted by other CDNTs in Ireland. However, there are several potential challenges to the success of such programmes. For instance, the LILAC programme is resource-intensive, requiring a wide range of health care professionals. Activity-based sessions depend on at least two team members, for intervention and observation. Their effective implementation relies on close coordination and efficient scheduling within the interdisciplinary team.

Facing the challenge of increasing healthcare expenses, LILAC exemplifies efficient resource utilisation in Ireland's healthcare landscape. Approximately 25 professional hours are allocated per child for a comprehensive service that includes assessment and intervention. This operational efficiency favourably compares with the estimated 15-35 hours reserved for assessment alone, according to Assessment of Need<sup>13</sup>. It demonstrates a cost-effective deployment of CDNT time and resources, thereby elevating the quality of care for patients and their families.

Many Irish CDNTs are currently facing staff shortages and lack of essential allied health professionals. For instance, some may not have the necessary expertise of clinical psychologist to diagnose ASD, using observational tools such as ADOS and CARS-2. Observational study may be hindered by the absence of physical infrastructure, such as a two-way mirror. Moreover, it demands parental involvement and availability on a weekly basis, which may not be feasible for working parents and single-parent families. The programme also depends on dependable private or public transport from their home to the CDNT location, which may be scarce in rural and low socio-economic status areas. Furthermore, the programme has so far only been tested in two cohorts of eight children and families each. It entails both individual activity-based assessment with parent and child, and group parental education sessions. The scalability of this approach has not yet been proven on a larger sample of patients. Additionally, LILAC has not been evaluated against a waitlist control group, in a randomised controlled trial.

Parent education sessions are a vital component of the LILAC programme. Current medical literature shows the impact of parental education on patient outcomes<sup>14</sup>. Research indicates that group parental programmes have been successful in enhancing the confidence and competence of parents of autistic children<sup>15</sup>. Due to social stigma associated with neurodiversity, these parents may be susceptible to low self-esteem and psychological wellbeing<sup>16</sup>. Parental coaching may improve morale and prevent self-blame, by equipping caregivers with pertinent knowledge and practical strategies for their autistic children.

In future practice, LILAC programmes should ensure to incorporate both relational (relationship-building) and participatory (competency-enhancing) elements, which are essential for an evidence-based model of family centred practice<sup>17</sup>. For instance, studies may consider aiming for an improvement in parental capacity, as well as confidence levels. Studies have demonstrated the success of parental coaching programmes in enhancing both parental capacity and confidence. Contributory factors for success included the provision of information, practical strategies, and parental support. Therefore, parental support should be a key component in future similar programmes.

To conclude, LILAC exemplifies a comprehensive approach to ASD evaluation, diagnosis and treatment. Its interdisciplinary approach embodies family-centred health care in a community setting. This mixed methods pilot study employs descriptive statistics and thematic analysis from a survey of interdisciplinary team members. In line with PDS principles, LILAC exhibits evidence-based practice, in accordance with the biopsychosocial model of care. Future studies may aim to measure a change in parental satisfaction objectively, using validated tools such as the Kansas Parental Satisfaction Scale.



**Declarations of Conflicts of Interest:**

None declared.

**Corresponding author:**

Cormac Duff,  
Department of Paediatrics,  
Galway University Hospital,  
Co. Galway,  
Ireland

**E-Mail:** cormacduff@gmail.com

**Acknowledgements:**

The authors are grateful to the allied health professionals of CDNT 6, Central Galway and Galway City East, for developing and implementing this pilot study. We appreciate the Paediatric Neurodisability doctors from Galway University Hospital, for their input to this innovative research. We express our sincere thanks to the parents, guardians and children who took part in this comprehensive approach to diagnosis and intervention in ASD.

**References:**

1. McConkey R. The rise in the numbers of pupils identified by schools with autism spectrum disorder (ASD): a comparison of the four countries in the United Kingdom. *J Autism Dev Disord.* 2020;50(12):4373-83. <https://doi.org/10.1007/s10803-020-04593-8>
2. Department of Health. Publication of prevalence of autism (including Asperger Syndrome) in school-age children in Northern Ireland 2022/23. Belfast: Department of Health; 2023
3. Greenspan SI. The development of the ego: implications for personality theory, psychopathology and the psychotherapeutic process. Madison (CT): International Universities Press; 1990.
4. Morris C, Horner RH. The importance of positive behavior support at the tertiary level. In: Sailor W, Dunlap G, Sugai G, Horner RH, editors. *Handbook of positive behavior support.* Boston (MA): Springer; 2016. p. 49-72. [https://doi.org/10.1007/978-0-387-09632-2\\_3](https://doi.org/10.1007/978-0-387-09632-2_3)
5. Whalen C, Schreibman L, Ingersoll B. The collateral effects of joint attention training on social initiations, positive affect, imitation, and spontaneous speech for young children with autism. *J Autism Dev Disord.* 2006;36(5):655-64. <https://doi.org/10.1007/s10803-006-0108-z>

6. Mesibov GB, Shea V. The TEACCH program in the era of evidence-based practice. *J Autism Dev Disord.* 2010;40(5):570-9. <https://doi.org/10.1007/s10803-009-0901-6>
7. Erbaş AN, Özcebe E, Esen TC. Investigation of the effect of Hanen’s “More Than Words” on parental self-efficacy, emotional states, perceived social support, and on communication skills of children with ASD. *Logoped Phoniatr Vocol.* 2020;46(1):17-27. <https://doi.org/10.1080/14015439.2020.1717601>
8. Schopler E, Van Bourgondien ME, Wellman GJ, Love SR. *Childhood Autism Rating Scale, Second Edition (CARS-2).* Los Angeles (CA): WPS Publish; 2010.
9. Lord C, Rutter M, DiLavore PC, Risi S, Gotham K, Bishop SL, et al. *Autism Diagnostic Observation Schedule, Second Edition (ADOS-2).* San Antonio (TX): Pearson; 2012.
10. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3:77-101. <https://doi.org/10.1191/1478088706qp063o>
11. Psychological Society of Ireland. *Best practice guidelines for the assessment and diagnosis of autistic spectrum disorders for children and adolescents (birth to 18 years).* Dublin: Psychological Society of Ireland; 2010.
12. Health Service Executive. *Progressing Disability Services for Children and Young People* [Internet]. Dublin: Health Service Executive; 2021
13. Community Operations Disability Team, Health Service Executive. *Assessment of Need Standard Operating Procedure (Disability Act 2005).* Dublin: Health Service Executive; 2023
14. Standards for need assessment [Internet]. Dublin: Health Service Executive; . Available from: <https://www.hse.ie/eng/services/list/4/disability/disability-assessment/standards-for-need-assessment.pdf>
15. Myers SM, Johnson CP. Management of children with autism spectrum disorders. *Pediatrics.* 2007;120(5):1162-82. <https://doi.org/10.1542/peds.2007-2362>
16. Farmer C, Reupert A. Understanding autism and understanding my child with autism: an evaluation of a group parent education program in rural Australia. *Aust J Rural Health.* 2013;21(1):20-7. <https://doi.org/10.1111/ajr.12007>
17. Cantwell J, Muldoon O, Gallagher S. The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities. *J Intellect Disabil Res.* 2015;59(10):948-57. <https://doi.org/10.1111/jir.12205>
18. James DE, Schumm WR, Kennedy CE, Grigsby CC, Shectman KL, Nichols CW. Characteristics of the Kansas Parental Satisfaction Scale among two samples of married parents. *Psychol Rep.* 1985;57(1):163-9. <https://doi.org/10.2466/pr0.1985.57.1.163>
19. Dunst C, Espe-Sherwindt M. Family-centered practices in early childhood intervention. In: Reichow B, Boyd BA, Barton EE, Odom SL, editors. *Handbook of early childhood special*

education. Cham (Switzerland): Springer; 2016. p. 37-55. [https://doi.org/10.1007/978-3-319-28492-7\\_3](https://doi.org/10.1007/978-3-319-28492-7_3)