

Impact case study (REF3b)

Institution: University of Ulster
Unit of Assessment: 4
Title of case study: Bringing a science of behaviour to the community
<p>1. Summary of the impact</p> <p>We addressed a serious mismatch between increasing rates of autism diagnosis across Europe and the shortage of professionals skilled in effective treatment provided by Applied Behaviour Analysis (ABA; www.bacb.com). A parent-lead charity (PEAT) was established in N. Ireland (www.peatni.org); teams from 7 European countries adapted our multimedia training resources (www.stamppp.com); Masters and Certificate level courses were established. Government documents informing policy in Scotland and New Zealand were corrected. Schools and charities in the Republic of Ireland, Poland, and Portugal, and other Masters level courses subsequently appeared in Ireland (http://tinyurl.com/cxpo66m). Simple Steps NI Ltd. was established involving PEAT and Manleys (http://www.manleys.co.uk).</p>
<p>2. Underpinning research</p> <p>The number of people diagnosed with Autism Spectrum Disorder has risen dramatically over the past decade. Whether this is caused by diagnoses becoming more precise, over-diagnosing, or an actual rise in incidents is a much-debated issue. In any case, recent studies have estimated that if not adequately treated the lifetime cost of care for an individual with an ASD can amount to as much as \$3.2 million. Therefore the issue of what constitutes the most appropriate response to diagnosis is very important (1, 3, 6). Getting it right can save enormously, not only fiscally (2) but even more importantly, it has major impact both socially and emotionally, i.e., in terms of quality of life for individuals, families, and society as a whole (4, 5).</p> <p>A comprehensive study of parental needs, showed that parental and professional views do not always concur; that families make extraordinary sacrifices; that siblings are affected; and that parents are under tremendous stress (4, 5). Parents argued that educational and social service supports are not efficient and that they are forced to rely largely on support from within the family or from friends. In particular, some important differences between parental and professional perceptions became apparent in relation to interventions. The importance of early and timely diagnosis and appropriate and socially valid educational plans was established (5). This research confirmed that having a child diagnosed with Autism Spectrum Disorder (ASD) poses challenges for families, many of which can be addressed through appropriate intervention and education. Results showed that parents whose children attend ABA-based schools are generally satisfied with their child's educational provision, monitoring procedures, and level of staff training, while parents who are not offered ABA-based schools rely on ABA-based home programmes (4).</p> <p>More recently, finding ways to facilitate knowledge transfer for parents who need help to deal with autism has been a major focus of Prof Keenan and this is evidenced by multiple translations of books into European (German) and Asian (Japanese, Hindi in preparation) languages. Over the past seventeen years he has also pioneered the use of multimedia in the teaching of Behaviour Analysis (6). His insights have led to the multimedia parent training pack SIMPLE STEPS which has been translated into German, Spanish and Norwegian, and presently is being translated into Portuguese, Italian, Icelandic, Dutch, and Swedish.</p>
<p>3. References to the research</p> <p>Conceptual</p> <p>Keenan, M. & Dillenburger, K., (2011). If all you have is a hammer ...RCTs and hegemony in science. <i>Research in Autism Spectrum Disorders</i>, 5, 1-13. doi:10.1016/j.rasd.2010.02.003</p> <p>Keenan, M., Dillenburger, K., Doherty, A., Byrne, J., & Gallagher, S. (2010). Experiences of parents during diagnosis and forward planning for children with Autism Spectrum Disorder. <i>Journal of Applied Research in Intellectual Disabilities</i>, 23, 390–397. 10.1111/j.1468-3148.2010.00555.x</p>

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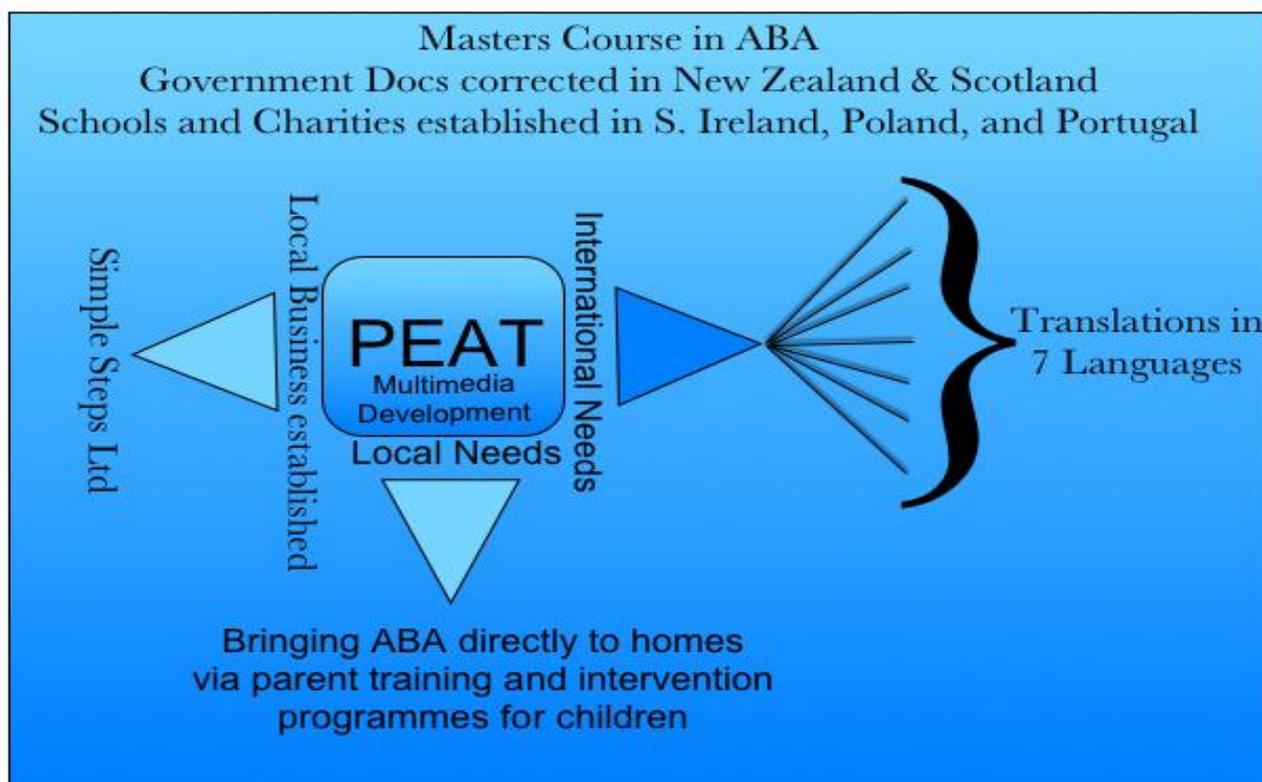
European Commission projects funded by Leonardo, Lifelong Learning Programme (LLP) (**STAMPPP**, 2008-2010 & **STAMPPP II**, 2011-2013, www.stamppp.com) totalled **€750,000+**.

Family needs

Dillenburger, K., Keenan, M., Doherty, A., Byrne, J., & Gallagher, S. (2011). ABA-based programmes for children diagnosed with Autism Spectrum Disorder: Parental and professional experiences at school and at home. *Child and Family Behavior Therapy*, 34, 1–19.

Keenan, M., Dillenburger, K., Doherty, A., Byrne, J., & Gallagher, S. (2010). Experiences of parents during diagnosis and forward planning for children with Autism Spectrum Disorder. *Journal of Applied Research in Intellectual Disabilities*, 23, 390–397. 10.1111/j.1468-3148.2010.00555.x

4. Details of the impact



N. IRELAND

The first parent-led Autism Charity in Ireland PEAT (www.peatni.org) was established by Prof Keenan in 1997. Over £11/2 Million raised; produced the first book in Europe on ABA (translated into **Japanese** and **German**, and **Hindi**); developed the first multimedia training program on ABA and autism (www.simplestepsautism.com) (**sample package attached**) (**Appendix 1**). See presentation by Chairperson of PEAT - <http://www.mediator.qub.ac.uk/ms/Quart/TByrne.m4v>

Business

Simple Steps NI Ltd., 20th April, 2010
(see presentation above by chairperson of PEAT)

Down's Syndrome

Dr Gallagher provides regular training events for The Down's Syndrome Association(Appendix 3)

Masters Training

The first Masters course in Behaviour Analysis in Ireland established in Oct. 2006 at UU. Eighty four graduates, twenty of whom have gone on to BCBA's practising in Ireland, United Arab Emirates and India. International standards of training in ABA (www.bacb.com) now included in job descriptions in HSC Trusts (Appendix 4).

REPUBLIC OF IRELAND

Over 13 schools inspired by workshops from Prof Keenan and his students. “Saplings was one of the first schools.. In financial terms our turnover for 2008 was €4.7 million with the Department of Education & Science funding approximately 85% of our turnover working out at €4 million.” (Marc de Salvo, Director) (Appendix 5)

Masters Training

5 Masters courses in ABA in the Republic of Ireland have followed on from PEAT’s work. The Division of Behaviour Analysis was established with Prof Leslie from UU as chairperson (<http://www.psihq.ie/division-behaviour-analysis>).

Invited Cross-party briefing on ABA and autism, Leinster House, Dublin (June 5th, 2013). Prof Keenan and Prof Leslie presented.

(<http://behaviouranalysisinireland.wordpress.com/2013/05/29/aba-experts-to-address-cross-party-briefing-in-leinster-house/comment-page-1/#comment-454>)

The National Council for Special Education (NCSE) (Sept. 11th 2013). Prof Keenan and Prof Leslie invited to present at their council.

PORTUGAL

A charity established in Portugal (<http://tinyurl.com/cwrj6cj>) inspired by PEAT along with a translation of **Simple Steps**.

“Their knowledge [i.e., Prof Keenan & Dr. Gallagher] and experience shared with us were crucial for the foundation of our organization” (Sérgio Baptista and Carla Martins, www.mykidup.com) (**Appendix 6**)

POLAND

The Lower Silesian Association of Behavioural Therapy for People with Autism (Active Mind) established in 2013 after workshops by Prof Keenan.

“Dr Keenan’s workshops have been of crucial importance for promoting the scientific and effective therapy for people with autism...” (Professor Małgorzata Sekułowicz) (**Appendix 7**)

SCOTLAND

In April 2009, Prof Keenan helped overturn misinformation on ABA in the Scottish Government document ‘The Autism Toolbox’. (**Appendix 8**)

European Funding

Leonardo da Vinci; Transfer of Innovation; *Science and the treatment of autism: A multimedia package for parents and professionals*. (**STAMPPP & STAMPPP II**) with partners from QUB, Germany; Spain; Norway, Sweden; Iceland; Netherlands; Italy; UU; PEAT (**€399,000 & €374,000 respectively**) (**Appendix 2**)

STAMPPP cited as an **example of excellence** by the European Commission at their 15th Anniversary meeting in Brussels (9th Nov., 2010). It also was selected as a case study by the **European Inclusion Initiative** (<http://www.llpinclusion.eu/default.asp>).

GERMANY

Simple Steps is used as an important didactic tool in the only academic education program for evidence-based interventions in ASD in Germany.

“Simple Steps has proved its immediate usefulness in therapy as well. (Prof Dr med. Hanns Rüdiger Röttgers) (**Appendix 9**)

Presentations by partners of STAMPPP II describe impact in their own countries. (<http://www.stamppp.com/events.html>).

ICELAND

The State Diagnostic Clinic will be using Simple Steps to spearhead training in ABA required by law. Nothing existed in Icelandic on ABA until the STAMPPP II project.

<http://www.mediator.qub.ac.uk/ms/Quart/SLoaJohnsdottir.m4v>

SWEDEN

Nothing existed in Swedish on ABA until the STAMPPP II project.
<http://www.mediator.qub.ac.uk/ms/Quart/LRollPettersson.m4v>

ITALY

Partners in the STAMPPP II project are now reaching a total of about 900 educators country wide.
<http://www.mediator.qub.ac.uk/ms/Quart/NPresti.m4v>

NETHERLANDS

Nothing on ABA was available in Dutch for parents until the STAMPPP II project.
<http://www.mediator.qub.ac.uk/ms/Quart/JSchenk.m4v>

New Zealand

Prof Keenan was on a lecture tour of New Zealand in 2003.

“The impact of this on the local ASD community is very measurable. There are now a number of BCBA Early Intervention providers based in New Zealand - this has reduced the reliance on overseas professionals at considerable costs to families. ” (Mary Henderson, ASD Kids Trust Trustee and co-Founder)

Along with other professionals, Prof Keenan persuaded the New Zealand Department of Education to revise their report on autism therapies because of the inaccuracies it contained on ABA (Dec, 2006). (**Appendix 10**)

Awards

Prof Keenan has received a number of awards: the Making a Difference award from the BBC (2002); Award for Promoting Equality of Opportunity, BPS (2002); Distinguished Community Fellowship, University of Ulster (2002/3); Personal Achievement Award, New York State Association for Behavior Analysis (2005); Fellow of the BPS (2006); Award for Public Service in Behavior Analysis from the Society for Advancement in Behavior Analysis (2008).

5. Sources to corroborate the impact

1. PEAT:- C/o Upper Springfield Development Co. Ltd., 689 Springfield Road, Belfast, Co. Antrim, Northern Ireland BT12 7FP, T: 028 9032 4882 E: info@peatni.org including Hard copy of Simple Steps
2. STAMPPP- Leonardo National Agency. Leonardo UK National Agency, Ecorys UK Ltd, Vincent House, Quay Place, 92-93 Edward St. Birmingham B1 2RA
3. Down Syndrome Association, Northern Ireland, Unit 2, Marlborough House, 348 Lisburn Road, Belfast, BT9 6GH Tel. 02890 665 260
4. HSC Trusts Job advertisement for person with BCBA qualification as an essential qualification.
5. Saplings: - Saplings Ltd., Kildare, Kilkenny, Dublin, Westmeath, Carlow (www.saplings.org)
6. Portugal:- Dr Sergio Batista (sergiofariabatista@gmail.com) (<http://mykidup.com/>)
7. Poland:- Professor Małgorzata Sekułowicz, Institute of Special Needs Education, Lower Silesian University, Wrocław
8. Scotland:- Christine D. Mahony, Email: christine.mahony@talktalk.net, Tel: 07724063219
9. Prof Dr med. Hanns Rüdiger Röttgers, M.A., M.A.E., Lehr- und Forschungsgebiet Gesundheitswissenschaft und Sozialmedizin, Fachhochschule Münster, FB10, Hüfferstr. 27, 48149 Münster.
10. New Zealand:- ASD Guideline Submission, Ministry of Health, PO Box, 5013, Wellington. Also, Dr Oliver Mudford, PhD, BCBA-D, Applied Behaviour Analysis Programme, The University of Auckland (Tamaki), Private Bag 92019, Auckland 1142, New Zealand, Telephone 64 9 373 7599 ext. 82319 Email o.mudford@auckland.ac.nz