

Forward Steps

Supporting pre-school children with autism

Julie Healy and Mary Anne Webb with
Barbara Crozier and Kevin McCormick

No. 9

Policy and
practice briefing



*'It has been invaluable
and helps to make you
feel supported as well as
giving practical advice.'*

Mother

BELIEVE IN CHILDREN

 **Barnardo's**
—Northern Ireland—

No. 9

Policy and
practice briefing

Forward Steps

Supporting pre-school children with autism

Introduction

It is estimated that 16,000 families in Northern Ireland are affected by autism (The National Autistic Society Northern Ireland, 2006). The numbers of people being diagnosed with autism continues to rise across the UK to the extent that autistic spectrum disorders (ASD) are more common than the combined total of multiple sclerosis, Down's syndrome and Parkinson's disease (Autism Cymru & PAPA, 2006).

About this briefing

This briefing paper looks at the importance of early diagnosis and intervention for children and their families, and in doing so it highlights the work of Barnardo's Forward Steps Service. Forward Steps is currently the only community based pre-school service in Northern Ireland specialising in assessing and supporting children with autism and moving them into mainstream or specialist provision.

What is autism?

Autism is a complex lifelong developmental disability, commonly referred to as autism spectrum disorder or ASD. The severity of the condition is frequently described as being on a spectrum that encompasses children with profound learning disabilities, with little or no verbal communication and children with average or high IQ, including Asperger's syndrome. However, everyone with the condition shares three main difficulties known as a triad of impairments (The National Autistic Society Northern Ireland, 2006). This includes some level of difficulty in relation to social interaction (difficulty with social relationships), social communication (difficulty with verbal and non verbal communication) and social imagination (difficulty in the development of imaginative play and repetitive behaviour).

Autism has a profound effect on a child/young person's development and is often difficult to treat. Classic autism can be identified in children as young as 18 months and is routinely identified by the age of 3. However, identification of broader autism spectrum conditions is poor and often not picked up until much later in a child's life, sometimes as late as their teenage years or in adulthood (Scott et al, 2002). Identification is problematic partly due to the broad range of features of social and communication difficulty that children may present.

A delay in diagnosis means children and young people do not receive the necessary services and support needed for healthy development. Research (Howlin, 2000) highlights a range of negative experiences and outcomes that can occur in these circumstances. Children and young people may experience bullying or isolation at school, develop depression or be at risk of antisocial, disruptive or anxious behaviour. Yet with early diagnosis and intervention many of these behaviours can be addressed (Bregman & Gertz, 1997) and children can be supported to reach their full potential.

A recent report evaluating need and early intervention support for children aged 2-4 years with ASD in Northern Ireland found that waiting time for assessment and diagnosis can be up to two years (McConkey et al, 2007).

Prevalence of autism

In the three year period between 2002 and 2005 the numbers of school age children in Northern Ireland with autism increased from 1,000 to 3,000 (Autism Cymru & PAPA, 2006). A survey by the Office of National Statistics of the mental health of children and young people in Great Britain found a prevalence rate of 0.9

per cent for autism spectrum disorders or 90 in 10,000 (Green et al, 2005). Another recent review suggests that ASD affects approximately 60 per 10,000 under 8-year-olds, of whom 10-30 per 10,000 have narrowly defined autism (Bamford Review of Mental Health & Learning Disability NI, 2006). Although there is agreement that the number of children with autism has been steadily increasing, prevalence estimates for autism do vary across studies. The National Autistic Society suggests that a prevalence rate of around 1 in 100 is a best estimate of the prevalence in children.

Forward Steps

Forward Steps is a unique Barnardo's Northern Ireland Service that expertly assists paediatric services in the assessment and diagnosis of pre-school children (18 months to 5 years) with autism and related communication difficulties. It also provides support and intervention to families and pre-school staff, post diagnosis. The aim of the Service is to ensure that children with autism are enabled to participate in everyday life including family, education and community settings. This is done by assessing each child's needs across different environments and developing individual programmes/interventions which can be adopted by family and educational staff.

The Service is based on the premise that, where there is a concern, children should be screened for autism as soon as possible and assessed. Forward Steps works intensively with each child to a timescale based on the individual's needs, which can be from eight weeks to ten months and provides the following distinct range of assistance for children and families:

- home based support
- assessment nursery

- early intervention programme including playgroup
- parent workshop/training
- parent and toddler group
- staff training
- outreach/direct inclusion work in the early years setting
- joint working with therapists
- summer activity club
- extended family support including grandparents groups and sibling groups.

All Forward Steps services are free for families and children who are referred from the Belfast and the South Eastern Health and Social Care Trusts. The Service currently has capacity to work with up to 50 children and families each year and recently moved to new, purpose built facilities. The additional space will enable the staff team to work with the children more efficiently and effectively. However, in order to generate greater capacity, a more substantial amount of statutory funding would be necessary.

Forward Steps services

Assessment Nursery

Children are referred to the Assessment Nursery when there is a concern with their development in the areas of social interaction, play skills and communication. This can be made by parental request through the Child Development Clinic or by a member of the Clinic itself. Forward Steps provides an assessment procedure within their Nursery, involving six weekly two-hour sessions where staff work closely with the child to assess their needs and also with parents/carers to support them through the process. Four children can attend at one time and receive one-to-one adult support. Assessment methods include play-based observations and the Psycho Educational Profile-3 assessment whereby play activities are used to assess all areas of child development.

The work in the Assessment Nursery is accompanied by home based support where the assessment and support continues in the child's home. Time is also spent observing the child in other environments that they may be attending such as nursery or playgroup. Staff offer individual support and advice to the family throughout the process

and the assessment concludes with on-site feedback to parents from a paediatrician. This approach ensures the parents/carers are meaningfully involved and informed throughout the process and helps prepare them for a diagnosis confirming that their child has autism.

'The support and understanding they gave towards myself and my son was useful. They helped me understand my son more and gave me confidence in dealing with problems that he has' **Mother**

Early Intervention Programme

This usually takes place after a diagnosis has been made, although in some cases, when the paediatrician and parents are in agreement and to avoid unnecessary delay, a child can attend the Early Intervention Programme while awaiting a diagnostic clinic appointment if their difficulties are consistent with those of ASD. In the new facility there are two playrooms which have each been specifically designed to support the needs of children at any point on the spectrum of autism. Each playroom is a small visually structured playgroup for four children at a time. There are three, three hour sessions each week in the playgroup and one home based session per week for each child.

Within the playgroups each child is assessed to determine both their level of development and degree of autism. A visually structured programme is then

put in place to support communication, learning and autism needs. Through daily one-to-one work sessions each child is supported and encouraged to learn age/developmentally appropriate self-help and play skills, participate in group activities including early social skills, and to gain their own level of independence.

A Key Worker helps parents/carers effectively support their child within the home in the weekly home session. This includes the parents/carers learning new skills in interacting with their child, managing challenging behaviour, introducing visual strategies at home and sharing information about the child's progress at playgroup. Importantly, this process helps parents/carers begin to better understand autism and to build on the progress being made through the programme.

The aim of this programme is to enable a child with autism to progress into local early years provision, mainstream or specialist depending on their needs, and to facilitate this, a careful handover with playgroup staff is arranged. Staff from the playgroup are invited to visit the child at Forward Steps and also meet the parents and receive information about the child's individual needs and personality. This is then followed up by Forward Steps who provide a staff member to accompany the child to their new playgroup for the first week to help them settle in.

Case study 1 (SK)

SK is a 4-year-old girl who, after attending her local nursery school for two months, was referred to Forward Steps Assessment Nursery to ascertain if ASD was an appropriate diagnosis for her social and communication difficulties. Following a detailed assessment, which included observations of SK both at home and nursery school, the Service Co-ordinator from Forward Steps met with the parents and the paediatrician to review the results and a diagnosis of higher functioning autism was made.

SK will continue to attend her local nursery and teaching staff there will use suitable strategies provided by Forward Steps. Her nursery teachers have also had the opportunity to observe SK in her final session at Forward Steps and discuss the strategies with staff there. Relevant information regarding SK's needs will be discussed at a handover meeting between Forward Steps, the parents and the ASD outreach service from the Department of Education which will continue to provide support to SK's teacher during her school education.

In order to maintain contact with other parents in the Assessment Nursery, SK's mother is going to attend the Mums, Dads and Toddler Group at Forward Steps and she has also accepted a place within the Parents' Support Group. SK's grandmother has been invited to attend the monthly Grandparents' Group and SK will also take up a place at the next Summer Activity Club.

'Forward Steps has meant so much to us as a family. Within a week of starting the programme D was able to understand the concept of the word 'No', something he hadn't grasped before. To have such focused and intensive support so early on is brilliant and is giving D the best start for his education and life at home. D is now able to make his needs known and screaming tantrums due to frustration are now very rare' **Parent**

Parent Workshops/Training

The parents of every child participating in Forward Steps are invited to the Parent Workshop which takes place while their child is at the Service. This enables parents to receive practical advice and guidance about how best to support their child's development, how to engage with other professionals and negotiate complicated systems ahead such as 'statementing', and how to access educational support. Parents also support each other and often maintain links with the Service many years after their participation.

'Experienced parents let you see that there is 'light at the end of the tunnel'... we have become more positive parents' **Mother and Father**

Parent Training provides parents/carers with information on TEACCH, the structured teaching method which is a recognised approach effectively used with children who have autism. This includes a practical session providing parents with the opportunity to make visual strategies individualised for their child.

Support for early years professionals

Forward Steps provides practical advice and training for early years workers through the Keyhole Training Programme in partnership with Early Years (the organisation for young children) and Autism NI. The Service also offers placements in the Forward Steps Playgroup for professional students and volunteers to raise awareness and pass on skills in relation to working with and supporting children with autism.

Family support

In addition to the specific programmes described, Forward Steps also provides a range of different support groups to help family members develop the necessary knowledge and skills to

meet both their own needs and those of the child with autism:

Mums, Dads and Toddler Group

Each parent/carer referred to Forward Steps is invited to the Mums, Dads and Toddler Group where they can find out more about the Service to which they have been referred. They can meet other parents and carers and get to know the staff team in an informal and friendly environment. There is no waiting time for this part of the service and parents are contacted within a week of Forward Steps receiving their referral from the Child Development Clinic.

'This was my first experience of contact with other parents of children who had similar problems to my son's. I found the discussions I had with both parents and staff invaluable' **Mother**

Grandparents' Group

This support group is for the grandparents of children with autism or who have a grandchild where there are concerns regarding their development in the areas of social interaction, play skills and communication. The group meets once per month and the group-led topics include information on autism, sensory processing, using art to explore issues and an opportunity to discuss in confidence concerns regarding their grandchild/ren. With increasing numbers of grandparents supporting families with childcare this group is important in supporting grandparents with caring responsibilities and those who simply want to help their families.

'The group was the first time I could laugh about things that my grandchild would do' **Grandmother**

Sibsclub

This club, run by Forward Steps and the Belfast Central Mission EAGLE project, is for children and young people aged between 6 years and their mid-teens who have a brother or sister with autism. They initially participate in seven weekly sessions after which they come along once per month. The groups are designed to be fun and informal but also to support and inform children living with a sibling with autism. A range of activities such as art are used to explore relevant feelings and issues.

Summer Activity Club

This is a four week programme open to any child who has attended the Assessment Nursery or Early

Intervention Programme during the previous year and has a confirmed ASD diagnosis. Each child has an adult carer and can take part in a range of activities, outings, sport and fun.

'Well run, well organised scheme, excellent staff, much enjoyed by my child and much appreciated by parents' **Father**

Service delivery based partnership and integrated services

Forward Steps works in partnership with a number of key agencies providing professional services for children and young people. Paediatricians, speech and language therapists and occupational therapists can all give an assessment within the Forward Steps facility, thus reducing the amount of appointments and travelling time for families. Well established and effective systems and working relationships have been developed with these professionals and Health and Social Care Trusts to ensure the swift and easy referral of children to the Service so that families receive a smooth, integrated service with as little disruption as possible. Forward Steps also works in close liaison with professionals from the education sector, including ASD specific Outreach Teachers and Educational Psychologists, to ensure that families receive a 'seamless' service as their children leave Forward Steps and move into education.

'The feedback from our parents and children using the Service is excellent. They feel they have received a very professional service from people who care for them and really understand their difficulties' **Consultant Paediatrician**

Availability of services in Northern Ireland

In Northern Ireland, the needs of people with an ASD are met by various providers including learning disability services. It is estimated however that two thirds of children with ASD will not have a learning disability and will therefore not be eligible for core disability services. Without alternative provision this results in the present situation in which there is a lack of appropriate services for children and their families across Northern Ireland.

Case study 2 (JT)

JT is a 3-year-old boy who has recently completed a six week assessment period at Forward Steps. He is not attending an early years service, however he receives speech and language therapy and occupational therapy from his local Health and Social Care Trust.

At the end of the Forward Steps assessment, JT was given a diagnosis of moderate ASD with accompanying sensory processing difficulties by his paediatrician. Following diagnosis JT was offered a long term placement in the Early Intervention Programme at Forward Steps. Working jointly with Forward Steps, therapeutic interventions will continue to be provided by speech and language therapy and occupational therapy services.

Forward Steps will continue to support the family during the Statementing Process and liaise with professionals from the Department of Education as necessary. The family currently attend the Mums, Dads and Toddler Group and have accepted a place in the Parents Support Group. A place at the Summer Activity Club will also be available for JT.

Forward Steps is currently the only community based pre-school service of its kind and there is a significant waiting list. Given the importance of early diagnosis and intervention, any delay may have very detrimental implications for children and their families. Forward Steps provides information and other support to parents/carers to help reduce the impact of the waiting time for assessment and diagnosis.

Funding and accommodation

The Forward Steps Service currently obtains approximately fifty per cent of its income from two Health & Social Care Trusts and the Department of Education (administered by the Early Years organisation). The remaining funding is provided from Barnardo's Northern Ireland voluntary funds, without which many more children would experience a long delay in receiving support. In addition, five years ago Barnardo's Northern Ireland embarked on an ambitious fundraising appeal to raise £750,000 to build a purpose built facility for children with autism, and also contribute towards the running costs until 2009.

Thanks to this successful fundraising effort, Forward Steps moved in October 2007 from limited accommodation in a Victorian house to the new building. This facility provides bright spacious accommodation and an increased space to divide children into groups according to their needs. It also offers an additional playroom to

facilitate both shorter term work to help children move into mainstream provision, and longer term more intensive work with children who have multifaceted needs. It is envisaged that this greater flexibility will enhance the flow of service delivery.

Fundraising and influencing work highlighting the lack of resources and services that are needed to maintain current delivery of the project, as well as expand its capacity, both remain a challenge for Barnardo's Northern Ireland and the Forward Steps Service.

Policy context

Statutory responsibility to deliver care that meets the needs of children with autism in Northern Ireland currently falls within the remit of Child Health, Mental Health and Learning Disability. This was acknowledged in the recent Bamford review of Mental Health and Learning Disability NI in which it was recommended that each Health and Social Care Trust designate a senior manager to co-ordinate the implementation of ASD services across all programmes of care.

There is vast professional experience and expertise in the field of ASD across various sectors. However, it is the responsibility of Health and Social Care Trusts to fund ASD diagnosis and early intervention. In addition, the Department of Education now has responsibility for 'early years' service and policy. Given that the optimum time for ASD diagnosis is between 2 and 3 years of age, this element of ASD services will

therefore fall within the remit of the Department of Education. This would indicate the need for a committed, working partnership between the Departments of Health and Education and the development of an inter-departmental strategy.

Best practice model

Barnardo's Northern Ireland advocates the earliest possible enrolment of autistic children in intervention services. The Forward Steps Service provides young autistic children the opportunity to interact with typical same-aged peers; offers them and their families a level of intervention that matches their needs, including all areas of developmental needs; and addresses challenging behaviour with positive, proactive strategies. These provisions echo the principles of good practice endorsed by the Northern Ireland Task Group on Autism (2002).

The Forward Steps Service began in 1999 using the Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) approach and is structured in a way that encourages a child to feel settled and relaxed. TEACCH addresses difficulties in organisation, memory, auditory processing and making transitions. Based on an understanding of the communication and social difficulties an autistic child can have, emphasis is placed on positive strategies of behaviour management.

The TEACCH approach is essentially characterised by seven key principles:

- **Improved adaptation** – through two strategies of improvement skills – education and modifying the environment to accommodate deficits.
- **Parent collaboration** – parents work with professionals as co-therapists for their children so that techniques can be continued at home.
- **Assessment for individualised treatment** – unique educational programmes are designed for all individuals on the basis of regular assessment of their abilities.
- **Structured teaching** – it has been found that children with autistic spectrum disorder benefit more from a structured educational environment than from free approaches.

■ **Skill enhancement** – assessment identifies 'emerging' skills and work then focuses upon these (this approach is also applied to staff and parent training).

■ **Cognitive and behaviour therapy** – educational procedures are guided by theories of cognition and behaviour suggesting that difficult behaviour may result from underlying problems in perception and understanding.

■ **Generalist training** – professionals in the TEACCH system are trained as generalists who understand the whole child and do not specialise as psychologists, speech therapists etc.

(The National Autistic Society)

Research has found that TEACCH programmes are effective in improving self-help, social skills and communication, the reduction of inappropriate behaviours, and enhancing quality of life, along with lower parental stress rates (Van Bourgondien et al, 2003). An independent review of the use of this intervention at Forward Steps concludes that the children involved made substantial improvements on a wide range of motor, perceptual and cognitive processes (Sheehy, 2000). In addition to improvements in the children's development, every parent indicated that they would recommend TEACCH to other parents. A range of other interventions or combinations of these are also practiced at Forward Steps including PECs, Icon to I Can, Keyhole and Principles of Sensory Integration, ABA, and Floortime.

'Forward Steps is a structured programme with lovely staff which has in such a short time improved my child's communication in an incredible way. Forward Steps is such a valuable resource, the key to it being it begins when children are so young. I wish it had been available for my older son who has Asperger's. We are so grateful to

have Forward Steps as it has given our son the best start possible. Great credit has to be given to the caring and skilled staff who tailor the programme to each individual child' Parent

Policy and practice recommendations

There is a clear need for government to establish consistent and cohesive policies and specific strategies for autistic spectrum disorders across Northern Ireland. The following policy and practice recommendations are consistent with the Northern Ireland Review of Mental Health & Learning Disability, the SHSSB Children's Autism Strategy and the work of 'Partners in Autism', a multidisciplinary group of practitioners, academics and professionals lobbying for a strategy for the delivery of autism services in Northern Ireland:

- There is a need for a co-ordinated Regional Strategy for the delivery of autism services across Northern Ireland to address gaps in provision, remove duplication and ensure consistency.
- The Departments for Health and Social Services and Education must work in partnership and develop an interdepartmental strategy for autism.
- There is a need for ASD policy documents in each Education and Library Board and at individual Health and Social Care Trust level in order to ensure consistent interventions are available to every child.
- A clear timeframe must be developed for assessment and diagnosis of children between 2-4 years of age. Where need is identified, support services should be provided as soon as possible. Health and Social Care Trusts must demonstrate a commitment towards, and investment in, early intervention provision.

■ Comprehensive training is required for professionals and early years practitioners in relation to knowledge and awareness of autism spectrum disorders.

■ Families must be actively involved in assessment and care planning procedures, and also appropriately supported to best meet their child's needs.

■ Service development should be based on the best available evidence of what works, therefore existing models of best practice should be adequately resourced to enable evaluation and dissemination of their practice.

References

- Bamford Review of Mental Health & Learning Disability in Northern Ireland (2006), DHSSPS
- Bregman, J & Gertz, J (1997) Behavioural Interventions in D J Cohen & F R Volkmar (eds) *Handbook of Autism and Pervasive Developmental Disorder*, pp 606-630 New York: Wiley
- Government and Autism: Opportunities and Solutions, (2006) Autism Cymru and Parents and Professionals and Autism Northern Ireland (PAPA)
- Green, H et al (2005) *Mental Health of Children and Young People in Great Britain, 2004*, Basingstoke: Palgrave Macmillan.
- Howlin, P (2000) Assessment Instruments for Asperger Syndrome, *Child Psychology and Psychiatry Review*, 5 pp 120-129
- Kelly, G, McConkey, R & Casey, J (2008) *A Strategy for the Delivery of Autism Services in Northern Ireland, Partners in Autism Northern Ireland with The National Autistic Society Northern Ireland; Due for Publication in early 2008*
- McConkey, R, Kelly, G & Cassidy, A (2007) *An Evaluation of the Need and Early Intervention Support for Children (Aged 2-4 years) with an Autistic Spectrum Disorder in Northern Ireland, DENI*
- Scott, F, Baron-Cohen, S, Bolton, P & Brayne, C (2002) *The CAST (Childhood Asperger Syndrome Test): Preliminary Development of a UK Screen for Mainstream Primary School Children, Autism 6(1) pp 9-31*
- Sheehy, N (2000) *Evaluation of TEACCH Methods for Pre-school Children with Autism, School of Psychology, Queen's University, Belfast*
- The Education of Children and Young People with Autistic Spectrum Disorder: Report of the Northern Ireland Task Group on Autism (2002), DENI*
- The National Autistic Society @ www.nas.org.uk
- Van Bourgondien, ME, Reichle, NC & Schopler, E (2003) *Effects of a Model Treatment Program, Journal of Autism and Developmental Disabilities 33 pp 131-140*



Barnardo's
–Northern Ireland–
BELIEVE IN CHILDREN

542-544 Upper Newtownards Road, Belfast BT4 3HE Tel 028 9067 2366

www.barnardos.org.uk

Barnardo's Registered Charity Nos. 216250 and SC037605 9820BO08