

SUBMISSION FROM BUDDIES CLUB PLAY SCHEME

1. Buddies Club Play Scheme was started by a group of parents in the west of Glasgow in October 1994. They all had children affected by disability and who could find no appropriate play and leisure facilities. Within weeks, the original Sunday club was full. Since then it has expanded to provide a range of services for children, young people and adults from age 5-35. The majority of these have autism. The services provided at present are-
 - After School Club - term-time only
 - Evening youth and adult groups - term-time only
 - The original Sunday club – term-time only
 - Holiday play schemes and youth/adult groups - during school and FE college breaks
 - Community outreach - all year round
 - Family support and home support
 - (There is also a nursery for 0-5 years aimed at local children and disadvantaged families).

Buddies Club Play Scheme fully supports the proposal for an Autism (Scotland) Bill

2. We acknowledge that a great deal of work has been done over the last 18 to 20 years to try to improve the lives of those affected by autism and their families. The PHIS Needs Assessment for Autism (2001) presented an excellent guide to the needs of people affected by autism and the range of support/services required to assist them lead as normal lives as possible. This document has produced some changes particularly the introduction of SIGN guidelines for diagnoses.
3. However, almost a decade has passed and the hoped-for changes to existing services and the introduction of new and innovative services to meet the life-long and pervasive needs of individuals affected by autism have not been followed through. At a local level in Glasgow, it should be acknowledged that the Autism Task Force, led by Councillor Christopher Mason, continues to provide excellent examples of good practice that aims to adapt main stream services to meet local needs.

Would people with autism in Scotland benefit from a national strategic approach?

4. Yes. A national strategy is required to ensure there are appropriate minimum standards and a nation-wide plan to help meet the needs of people with autism and ensure the correct services to meet these unique needs are in place. In contrast to the good practice guidelines and teaching and training aids available that have not produced the changes needed on the ground, the introduction of legislation would provide the “teeth” that have been missing over the last two “lost” decades. At the moment the word “guidance” is used within the Bill and, although

we strongly agree with the requirements for the Minister to provide leadership, our parents are concerned that “guidance” will not be strong enough to bring about the changes that are needed to meet the needs of families who live with autism. The Autism (Scotland) Bill requires “guidance” to be prepared on the following-

Autism Diagnostic services

5. There has been improvement in this area but many children and young people are still being missed at important times in their lives. The introduction of “Health for all children 4 200” means that many babies are classed as having “core” needs and the first signs of autism or any other developmental delay are not being identified at an early stage. This often results in late childhood diagnosis and the missing out on any early interventions that might be available with diagnosis. There are still considerable numbers of children making their way through mainstream primary school without diagnosis and crisis only comes on transition to secondary school. Even when diagnosis is obtained there is no follow up plan given to many schools and it is almost impossible for many to obtain a Co-ordinated Support Plan (CSP) under the ASL Act. The number of exclusions due to lack of appropriate support or knowledge of needs continues to be of concern. Adult diagnosis continues to be patchy and extremely difficult resulting often in individuals suffering unnecessary mental health issues or even finding themselves within the criminal justice system before a diagnosis takes place.

Identification of persons with autism

6. This continues to be difficult for a range of reasons including non-diagnosis. Many children and young people even with a diagnosis are known solely to education and receive no social work input until the date arrives when they are eligible for adult services. The “E-Say” project should identify most people with autism and learning disability but many with Asperger syndrome remain uncounted, unidentified and un-supported.

How the needs of people with autism should be assessed

7. This still remains an area requiring a great deal of work. It is often presumed that this is an “education only” issue. There have been vast improvements in education but many still miss out as there still insufficient specialist placements and CSPs are difficult to obtain. Our families need more than an educational placement and are looking for appropriate play and leisure facilities as outlined in PHIS. A holistic approach to services needs to be developed nationally and a range of needs assessed beyond the single dimension of educational requirements.

How services should support young people with autism when they leave school

8. This area needs significant input. Plans should be made well in advance of a school leaving date. It is still in most cases a “take it or leave it” range of services offered to those who require significant support and in many cases people are having to accept services which do NOT meet their needs. The unique difficulties faced by people with autism require a national set of standards and approach.

Significant resources are often wasted due the inability for services to be more innovative, adventurous and pro-active and to fit the broader autism profile. It is to be hoped that the implementation of personalised social care in Glasgow will result in improvements to services. We hope that NEW INNOVATIVE SERVICES will be available under this scheme and not just the present “same old story”!!

How other services should be planned

9. This is where all the excellent work and ideas already available should be implemented. Joint working with parents/carers and the young people themselves could produce significant change without vast resources having to be spent on research into what works. Vast amounts of time and resources have already been spent developing what is recognised as “good practice”.

Training for people who work with people who have autism

10. There is a vast range of excellent material available. Legislation should ensure that, through a national framework, the correct training is available for everyone who works with and supports people with autism. This is particularly important with front line staff at practitioner and support worker level who often have the most influence on the day to day lives of people affected by autism.

How local services should work together

11. This should bring together everyone who has any contact with people affected by autism including all statutory services and those within the voluntary sector. It should also be recognised and accepted that some people affected by autism will require very specialist services. If these are introduced early, VAST improvements will be made to an individual's life and future resources will be saved. Significant outlay at point of diagnosis with appropriate assessment and service provision will produce much better outcomes for all concerned and at great future savings for the public purse.
12. We acknowledge that there many other areas which require addressing and need to be introduced within an Autism (Scotland) Act. We note with pleasure that individuals affected by autism have given their own responses to areas we have not mentioned. In conclusion, while we agree that an autism strategy is required, we absolutely believe that it requires to be backed by an Autism (Scotland) Act, a belief that is supported by almost two decades of working at a local level to support parents, carers and those who live with autism.

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