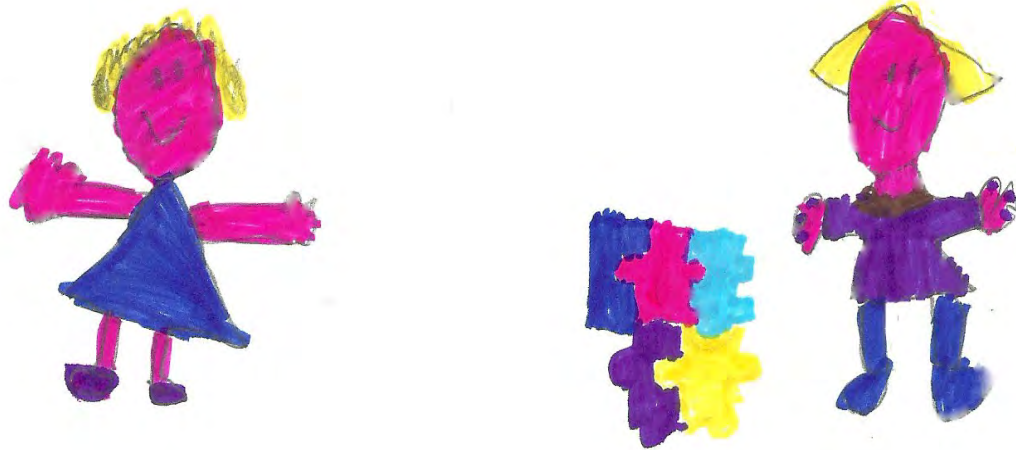


# BEING A PART NOT APART

**A Report on Inclusion from Highland Children's Forum**



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Highland Children's Forum  
2013**

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## Chairperson's Foreword

When my son was diagnosed with complex autism and severe learning disabilities at the age of 3, we leaned heavily on a small and close group of family and friends to support us through the grief as well as through the practicalities that went along with adjusting to life with Matthew's increasingly apparent needs. In particular, I found a sturdy shoulder (on top of which was a very knowledgeable head!) in a friend who has a daughter, now in her 30s, with autism and other health issues. She assured me that when her daughter was 3, as Matthew was then, things were very different. She'd had to fight tooth and nail for the services that her daughter needed. She had, in her own words, "blazed a trail" for future children with autism and their families. This provided me with a sense of security at the time, knowing that there were people and services out there that were ready in the wings to meet our needs.

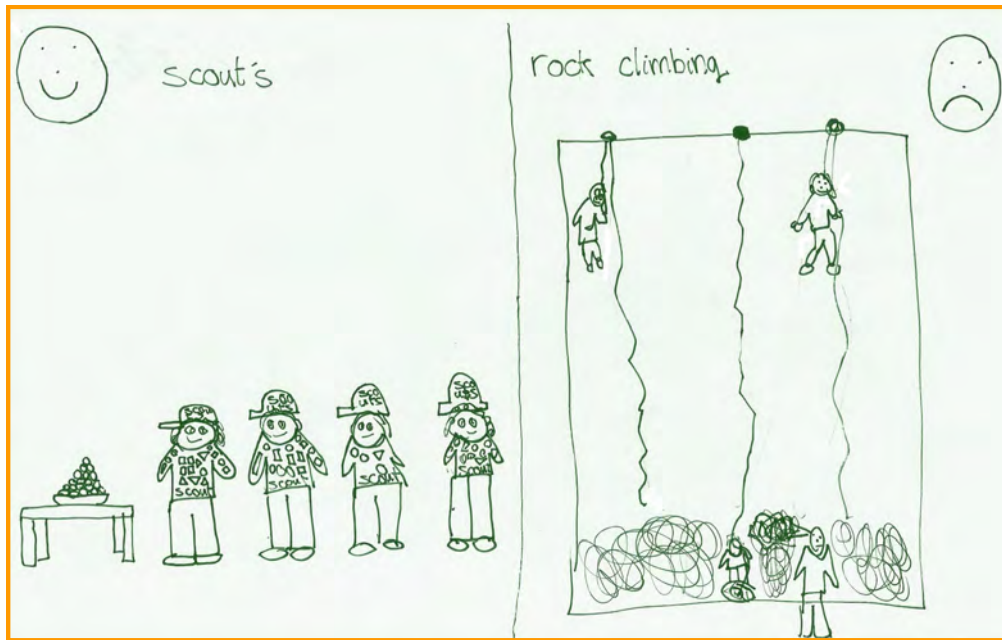
Mmmm. Not quite so. 13 years on and I feel like I too have "wrestled" my way to where we are now. It hasn't been easy to access the services that we've needed at the times we've needed them. And recently I was speaking to a younger Mum with a little boy with complex additional support needs, who had received some appalling health care in the first weeks of his life. She's just setting out on their journey into schooling and she mentioned the "battle" she went through to ensure her son received nothing short of life-saving healthcare as well as the attitudinal barriers to mainstream education they are now facing.

One would be right to argue that each of our pathways through service-land would necessarily be quite different. Every child is different and requires a package of services that is tailor made to their needs. But why does every parent feel that they've had to *battle* to get what they need for their child? Personally, we've come across some excellent professionals over the years who've been proactive, creative and have really cared about our son. Many times however, and often when we've been most needy of help, we've been subjected to some very mediocre, bordering on sub-standard service providers who have been lacking in basic ability, "jobs-worth" in their attitudes and who, quite frankly, should reconsider their career path! These negative experiences take their toll on families at these difficult times and can easily over-shadow other positive outcomes, especially when parent-carers are physically, mentally and emotionally drained from their caring responsibilities.

And of course bureaucracy gets in the way when even the best service providers, who want to do their best by a young person, have their hands tied by budget constraints or other environmental factors out with their control.

So, what to make of all this? Just like the title of the HCF report from 2008 on Inclusion, I ask the question once again, "Are we there yet?" The short answer is "No". The question that this report poses, on the back of the 2008 project is basically, "Are we any closer than we were then?" Maybe not but there is a feeling from this report that we are certainly no further away and maybe service provision is marginally better. A shift in the attitudes of a whole society takes time. A fully inclusive society will take many more generations of shaping and developing. We are a work in progress, as long as we learn from mistakes, shout about good practice from the rooftops and above all, keep our children and young people at the centre, we're heading in the right direction.



*Isabel Paterson , June 2013*



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## Abbreviations

HCF: Highland Children's Forum  
C&YP: Children and Young People  
YP: Young People  
SDS: Self Directed Support  
PVG: Protection of Vulnerable Groups  
CDC: Council for Disabled Children  
PINS: Pupil Inclusion Network Scotland  
HMle: Her Majesty's Inspectorate of Education  
CIS: Children in Scotland  
ASN: Additional Support Needs  
ASC: Active Schools Co-ordinator  
YDO: Youth Development Officer  
ASD: Autistic Spectrum Disorder  
PMLD: Profound and Multiple Learning Disability  
CSW: Children's Support Worker  
OCD: Obsessive Compulsive Disorder  
CfE: Curriculum for Excellence  
DDA: Disability Discrimination Act  
GIRFEC: Getting It Right For Every Child  
ADHD: Attention Deficit and Hyperactivity Disorder  
HYV: Highland Youth Voice  
SDS: Self Directed Support

Sometimes at break time I have  I feel included when my friends are listening to what I'm saying and including me in the games and everything.   
I feel left out when the other girls are playing a game I don't like, but I don't ever really feel left out.

## **Acknowledgements**

Thanks are due to

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## Introduction

Highland Children’s Forum consulted on Inclusion in 2005 (“What Difference Would There Be If Children’s Experience Framed Policy?”). Inclusion was also part of the “Are We There Yet?” study in 2008. It was proposed that this report would revisit some of the issues of the previous reports to ascertain whether the picture of inclusion was one of improvement for Highland children and young people, particularly those with additional support needs (ASN).

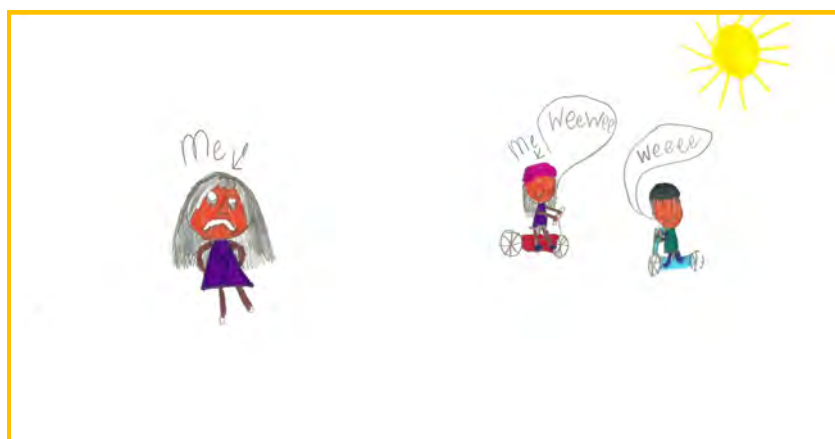
This consultation ran from June 2012 to May 2013 with 505 children and young people (C&YP) being consulted within 20 groups in educational establishments. There were 31 C&YP in 4 special school or further education access groups. 10 individual young people were separately consulted. 18 parents were consulted within 3 parent/carer groups and 9 individual parent/carers. 23 providers were consulted.

Providers seemed, without exception, keen to take part in the consultation and discuss inclusion, with some commenting that it was a good opportunity for them to revisit inclusion and to reflect on it within their organisation.

Schools were for the most part willing to take part, though there seemed to be some initial ‘suspicion’ from some during the planning stages. Whilst most schools were co-operative partners in the process there were a few schools who, even allowing for the pressures under which they work, were not very efficient or welcoming, begging the question of their commitment either to inclusion or to consultation with C&YP (e.g. admin. staff/class teachers not expecting me, schools who had forgotten I was visiting, schools that had not sent out the consent forms).

The visits were all as a result of invitation or agreement so there is an element of self-selection by participants. Some of the responses were anecdotal and HCF has not verified them, so cannot claim that they are representative of all experiences of inclusion. However, they were real experiences and opinions to those who contributed them, and as such, are important and valid and should be taken seriously.

This report tries to address the issue of inclusion in its broadest sense. It will be appreciated that it is a very complicated topic with a range of meanings and understandings which are context - dependent. A research section (page 54) attempts to clarify and define inclusion.



## Method

It was decided to consult with the general school population (which contains a number of C&YP with a range of additional needs), C&YP with some specific individual needs and C&YP in specialist provision. In order to achieve some balance within the project and, in order to ensure that all perspectives were considered the views of providers and also of parents were sought.

An urban, a rural and a sparsely populated area of Highland were chosen so that there was demographic balance. The associated school group (ASG) within each of these areas was approached with the proposal. So that schools were offered maximum flexibility they were asked to facilitate access to an *older* group and a *younger* group, the exact age and size of which was determined by them as was convenient.

As Highland Children's Forum (HCF) has some understanding and sympathy for the pressures of time and curriculum within schools it was proposed to use methodology which would take the form of an activity relevant to the Curriculum for Excellence which would help to ensure school buy-in and would also ensure that the C&YP would gain from the experience and not merely provide responses. Schools were visited, C&YP consulted and head teachers/deputies spoken to face to face.



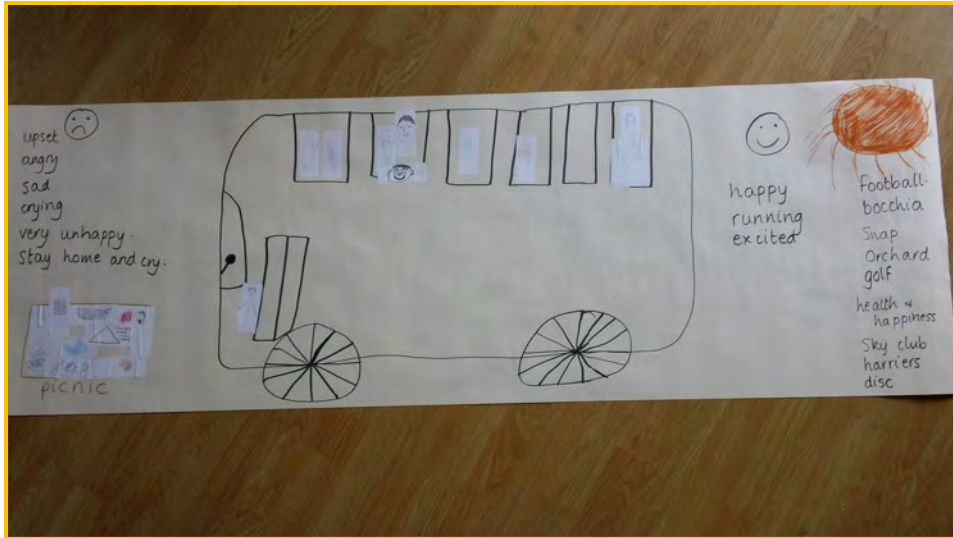
The activity was divided into 3 parts:-

- The group was asked what activities they attended outside school and this information was tallied.
- An activity to refine understanding of inclusion– young primary pupils were read 'Nothing' by Mick Inkpen, older primary pupils were read the Roald Dahl version of 'Cinderella' and secondary pupils were asked to imagine a scenario in which they were involved in the running of community provision and had to convince would-be users that everyone was welcome.
- The C&YP were asked to draw/write about a time when they felt included and a time when they felt excluded. (There were a very few occasions when this or the tallying activity did not take place, due to time constraints or the limits of the understanding of the YP.)

A group story of an imaginary journey was the context for very small groups and for groups whose cognitive abilities meant that they could not access the more structured activities described above.

The head teacher (or deputy) of each school was asked to discuss what contributes to inclusion and what barriers there are to inclusion in their schools. They were also told of any inclusion issues within school that the children had brought up during the consultation and were asked about C&YP on roll but not attending.

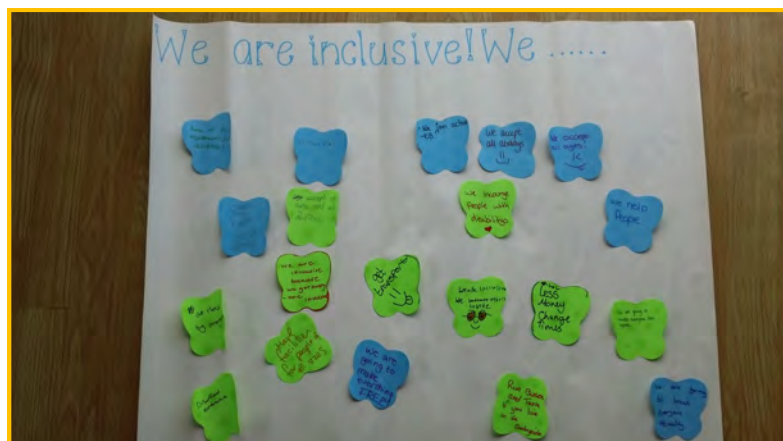




Individual C&YP who were consulted separately were invited to discuss and respond regarding their school and out of school activities in a way that they were comfortable with, with some needing some visual prompts to aid understanding. Providers were asked questions relevant to their provision to establish what they feel contributes to inclusion and what constitutes a barrier to inclusion. Parents were seen either by visiting established groups, or as individuals, and were also invited to discuss what they feel contributes to inclusion and what constitutes a barrier.

Consent was obtained for all individual C&YP participants who were over 12 and parental consent was also obtained for under 12s. Though consent was not needed to carry out the school activities as it was relevant to the CfE and therefore constituted part of the curriculum offer, some schools opted to put forward only those C&YP for whom there was consent. However there is consent for all the drawn, written and quoted responses within the report. Consent was obtained from all parent participants.

Primary evidence and personal details for this consultation will be stored by HCF in accordance with its policy and with current data legislation. Where names have been used they have been changed to protect anonymity.



## Summary

In considering the evidence from C&YP in schools it was heartening to see that it is evident that they, especially at primary age, attend a huge range of activities, both in number and variety. It was also heartening to see that the most common response to feeling excluded was that of never having felt excluded. There was a greater attendance at youth club and a much greater take up of instrument tuition in the sparse area than in either the urban or rural areas. There was also a good uptake of activities organised by the ASCs (active schools co-ordinators) in all three areas. When considering where they feel included and excluded it can be seen that contexts involving friends and family score high in both the included and excluded responses reflecting the importance of friends and family to the well-being of C&YP. There seems to be a correlation between feeling included/excluded and happiness and well being, self esteem and confidence.

Though the individual C&YP had a number of positive experiences to relate there were a number of barriers to their inclusion, particularly structural ones, mostly of an avoidable nature. The individual C&YP consulted had experienced varying levels of support and understanding. The ones who had had an early diagnosis at the beginning of their school life seemed to fare better than those for whom diagnosis came later. The early diagnosis perhaps led to better understanding of their behaviour, and ensured that they had their needs met from an early stage in their school life. For the C&YP who are either non or part attenders of school, particularly those with ASD (autistic spectrum disorder), the amount of support was not the critical factor it was the school environment with which they could not cope. The lack of any viable alternatives seriously compromises both the education and the inclusion of these YP who need solutions which will take account of their individual needs.

Head teachers seemed to see the positive ethos and staff attitudes as the most important factor in engendering an atmosphere of tolerance and inclusion where all children had a voice, and there were a number of initiatives to support this. Also considered to contribute to inclusion were a well-designed and attractive school environment, partnership working amongst small schools, access to external services/agencies and appropriate staff to support ASN, and finally changed strategic policies supporting the attendance of itinerant groups previously typically not attending.

Alongside ethos and attitudes, availability of transport was seen as absolutely fundamental, allowing C&YP to take part as active members of both the school and wider community.

The school buildings were the barrier to inclusion most often cited by head teachers with rurality and the effects it has on extra-curricular activities, provision of staff cover, volunteers, also a major issue.

The effects of integration of some C&YP with ASN on the other children was also an issue that head teachers brought up.

Staff concerns of cover and the difficulties of maintaining a sufficient level of expertise in dealing with ASN across a small staff were mentioned.

The effects of budget cuts and the long-term effects on inclusion was causing concern and there was a perceived lack of equity, with rural schools feeling that urban areas have the benefits of proximity and sparse areas had extra funding, leaving rural feeling disadvantaged.

Parents felt that there have been improvements in access in the recent past and that environmental barriers were relatively minor. Whilst there were some positives parents also gave a number of negative examples. These would, for the most part, be simple to remedy with a little thought and could be avoided completely if the views of the 'experts', the service users and their families, were sought at design stage. For C&YP with physical disability the major issue was personal care. Most of the issues were of the suitability of environments, particularly mainstream school for C&YP with ASD with parents feeling that no matter what support was put in place these C&YP could not cope with the sensory and social elements of school.

Many of the structural barriers were around communication issues - poor communication within and between organisations, meetings, lack of information, disregard of parents' views. Lack of flexibility and availability of respite and out of school provision was commented on and transport evoked strong words. There was a strongly held view that there was a determination at strategic level to enforce a policy of inclusion for all even when it was obvious that it was not benefitting the C&YP and that schools have to 'make the best of a bad job'. Staff shortages within services, lack of consistency of staff and levels of training and expertise were all issues raised.

Parents appreciate the services provided by most professionals with whom they deal. However it became clear that, as with other HCF reports (Recipe for Young Parenthood 2012, and How's Your Journey 2012 ), the attitudes of professionals can be very variable. This is particularly important with those who lead groups because attitudes which they are modelling to the group affect the ethos and the level of acceptance and support that the group offers.

Providers felt that there are still some problems with barriers to inclusion; with venues, location and transport being the major environmental barriers; with suitability, adaptability, availability all being mentioned.

Of the structural barriers perhaps training emerged as the major issue with availability of affordable training, the difficulties of having sufficient expertise within a staff team and of enabling volunteers to access training to meet the needs of the C&YP they encounter all cited.

Communication and the attitudes of services and professionals are still issues and there seems to be a lack of confidence that measures to better integrate service provision are working.

The picture, though it does not show significant improvements in the experience of inclusion over the 8 years since the last HCF report on inclusion (What Difference Would There Be If Children's Experience Framed Policy" 2005 ) does not seem to show significant deterioration either, though there seems to be some crystallisation of views e.g. the parents' view that mainstream is not the right place for C&YP with ASD. There would be serious implications for the support of inclusion and ultimately for C&YPs' experience of it should the budgetary situation become more challenging.

## What Children and Young People in Schools say about Inclusion

C&YP were asked what activities they did outside school. The C&YP offered the information without prompting beyond an occasional and spontaneous reminder from another child. Activities which take place in school but out of class, including instrument tuition, were also included. So there was a mixture of school organised activity and activity organised through clubs, ASCs (Active Schools Co-ordinators), YDOs (Youth Development Officers) and family.

Some groups elaborated and discussed activities they used to, but no longer, access and/or activities that they would like to access but are unable to. The most common reasons for not attending an activity that they would like to were around costs and distance/transport, though bullying and unfriendly people were also mentioned.

The C&YP who discussed what they would like to see, talked about a range of activities not provided, but some talked about enhancements to their environment e.g. short circular paths for walking, cycling, riding and restoration of an already existing but unusable pitch.



As the discussions were structured in order to prevent C&YP from feeling exposed or embarrassed it was not always possible to quantify exactly how many C&YP did not access any leisure activities at all, but the impression was that there were very few. However, it was noticeable that, of the C&YP who did not attend any activities, there were 5 in one primary school group (all requiring support), and 3 of 9 in college access groups. This could suggest some correlation between ASN and uptake of activi-

ties. The college groups had attended many activities but had given them up for a variety of reasons and their verbal responses and body language showed a degree of bluster and defensiveness.



It will be seen from the charts on pages 16-21 that the urban ASG had access to the greatest range of activities, with a range of 63 attended overall. This included a number of groups which were provided specifically for C&YP with learning or physical disabilities. The rural ASG area had a range of 61 activities and considering the fact that the urban range included the specialist disability provision this figure for the rural area seems comparatively high. The sparse ASG area had a range of 32 activities. The diminishing range reflecting the fewer population numbers and the greater transport and venue issues of the sparse area.

In the smallest and most isolated primary school in the sparse area the head teacher relayed comments from the parents that the children did not feel excluded and accepted the status quo, not realising that things could be different. The only out of school option for these children was the after-school club once a week which they all attended. They were 2 hours from a town and school swimming was a whole day trip.

Some groups across all 3 areas were of the opinion that at after school clubs "you don't do anything there—you just wait for your parents"

Many of the special school students only attended groups which were specifically provided for C&YP with disabilities, though some attended mainstream sports clubs also.

There were some students who would have liked to attend specialist provision but were unable to as there were long waiting lists. Discussions with specialist provision revealed that they feel that YP with disability become increasingly isolated as they get older; the gulf between them and their peers widens and it is increasingly difficult to provide for the breadth of needs and interests in mainstream leisure provision.

The young disabled people, therefore stay with the specialist provision and this lack of throughput means that it does not have the capacity to take in new members



It can be seen from the charts that C&YP accessed fewer activities as they got older, with primary pupils accessing a far greater range than secondary. The YP reported that this was due to a combination of increased studying and part-time jobs resulting in less time. There was also a perception that most opportunities were sport related and that there was little for those YP who were not interested in sport. It reflects a stated desire to just be with mates, not necessarily doing anything structured and may also be a consequence of narrowing the range of interests as they become more intensely involved in fewer activities.

It is noticeable that in the sparse area, though there are fewer different activities they are attended by a higher number of the C&YP than are activities in the urban and rural areas, where many activities are attended by only one or two C/YP from the groups consulted. The C&YP in the sparse area are possibly mixing with their school friends in social activities too and will not have access to as wide a social circle as the C&YP in urban or rural areas.

Whilst most C&YP accessed something, the discussions revealed that in some primary groups there was a hard core of C&YP who accessed almost everything that was available.

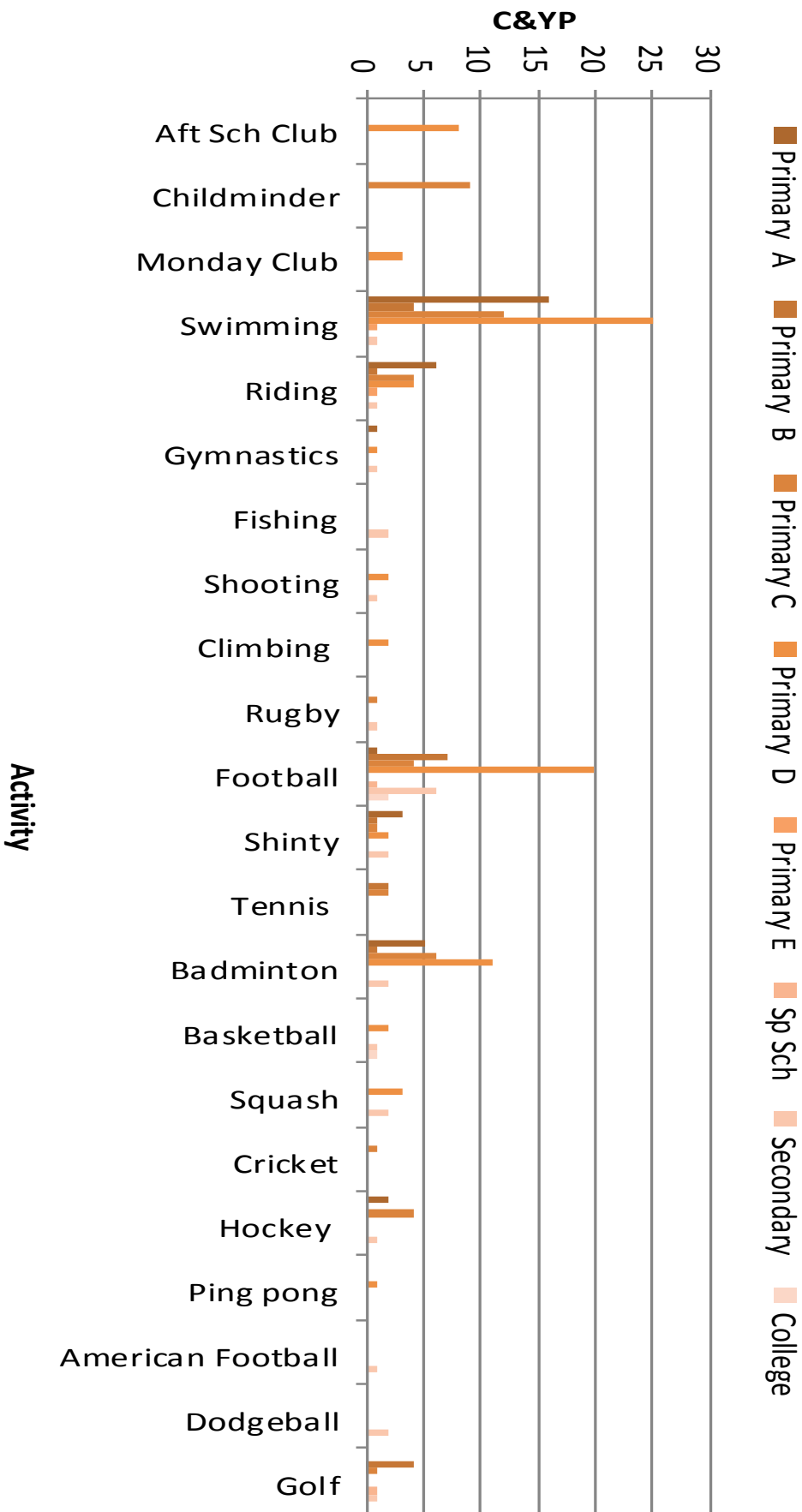
There seemed to be a greater dependence on the activities provided by the ASC and YDO in the rural and sparse areas. The activities provided by them seemed to be well-used in all areas to the extent that the staff reported it being difficult to get extra time-slots in the venues available to them. Youth club was the dominant activity in the sparse area with 45 children of 114 (39%) attending compared with 1% in the rural area and 3% in the urban area. This figure does not take account of the fact that the youth club provision was only open to 8 + years so represents a higher percentage of attendance of the eligible age group. It is also noticeable that many of the range accessed are sporting, or active e.g. dance.

Interestingly music was accessed much more in the sparse area than in rural or urban areas, with 53 of 114 (46%) of C&YP playing an instrument compared with 45 of 175 (26%) in the rural area and 22 of 216 (10%) in the urban area.

Across the 3 areas swimming is the activity which most C&YP attend. Many attended with school; some also attending swimming lessons or going with the family or both. The public swimming pool was 2 hours away for some of the sparse area, though many in both the sparse and rural areas were able to use private hotel pools.

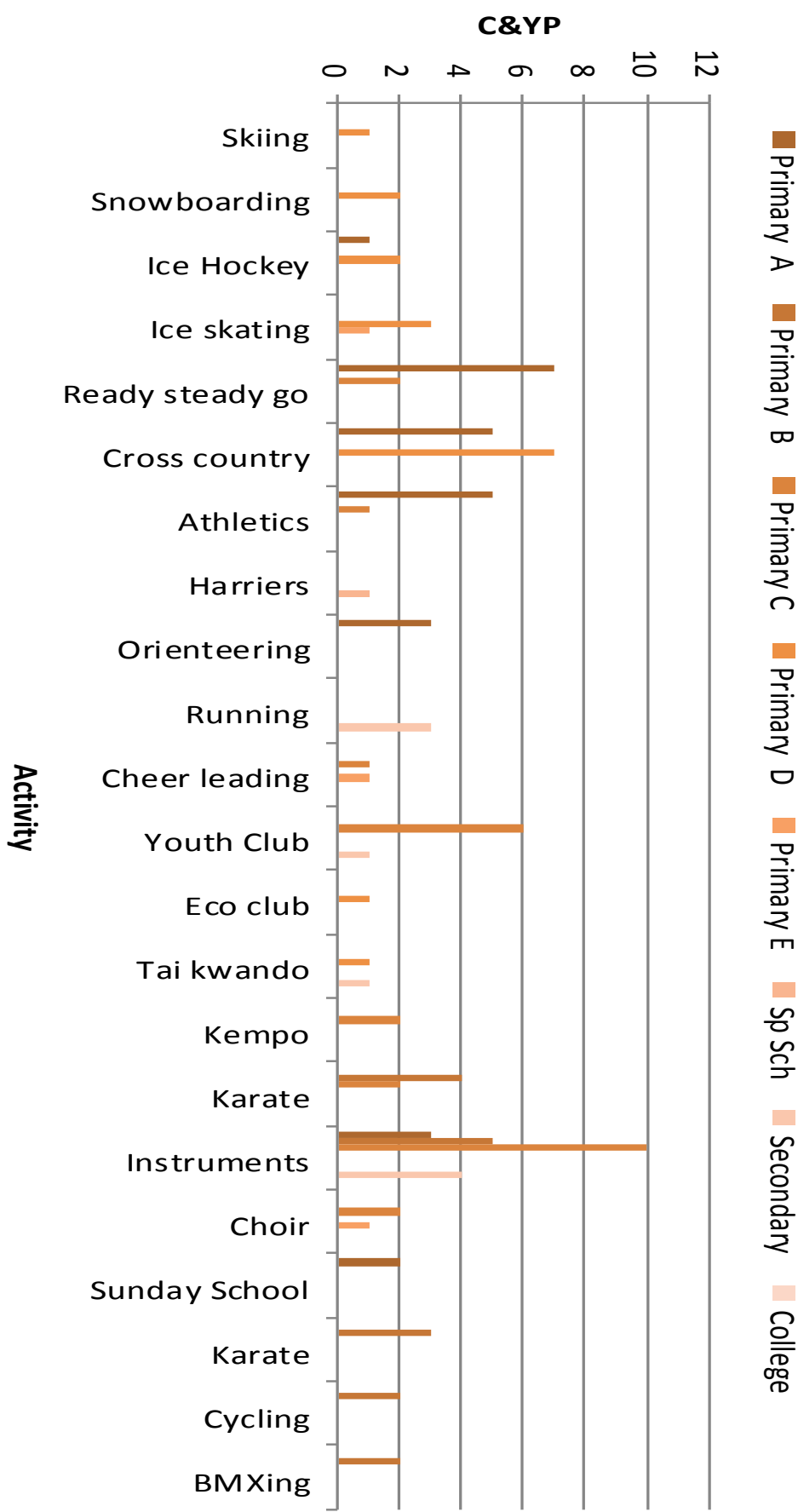


## Activity Range: Urban ASG

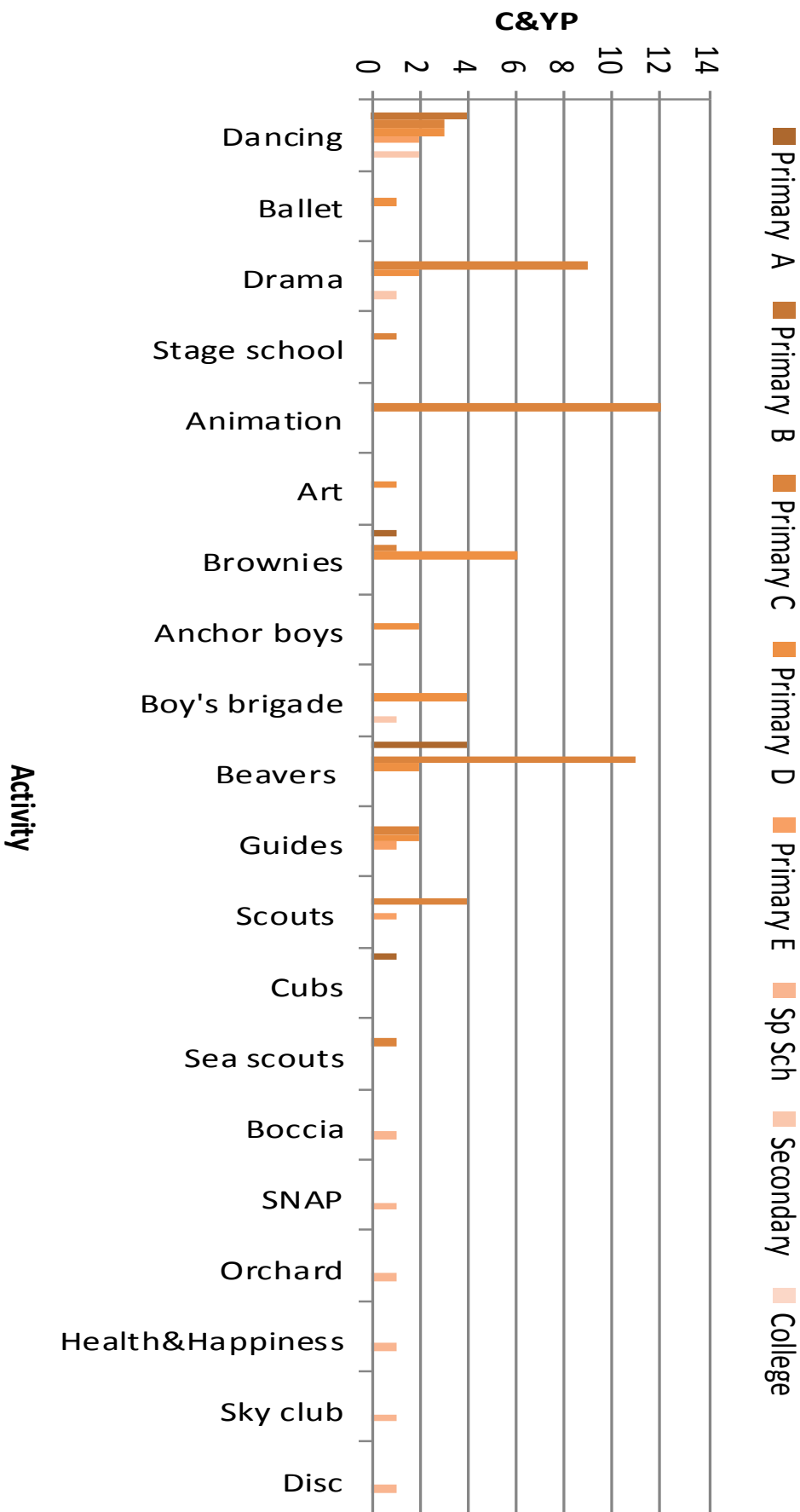




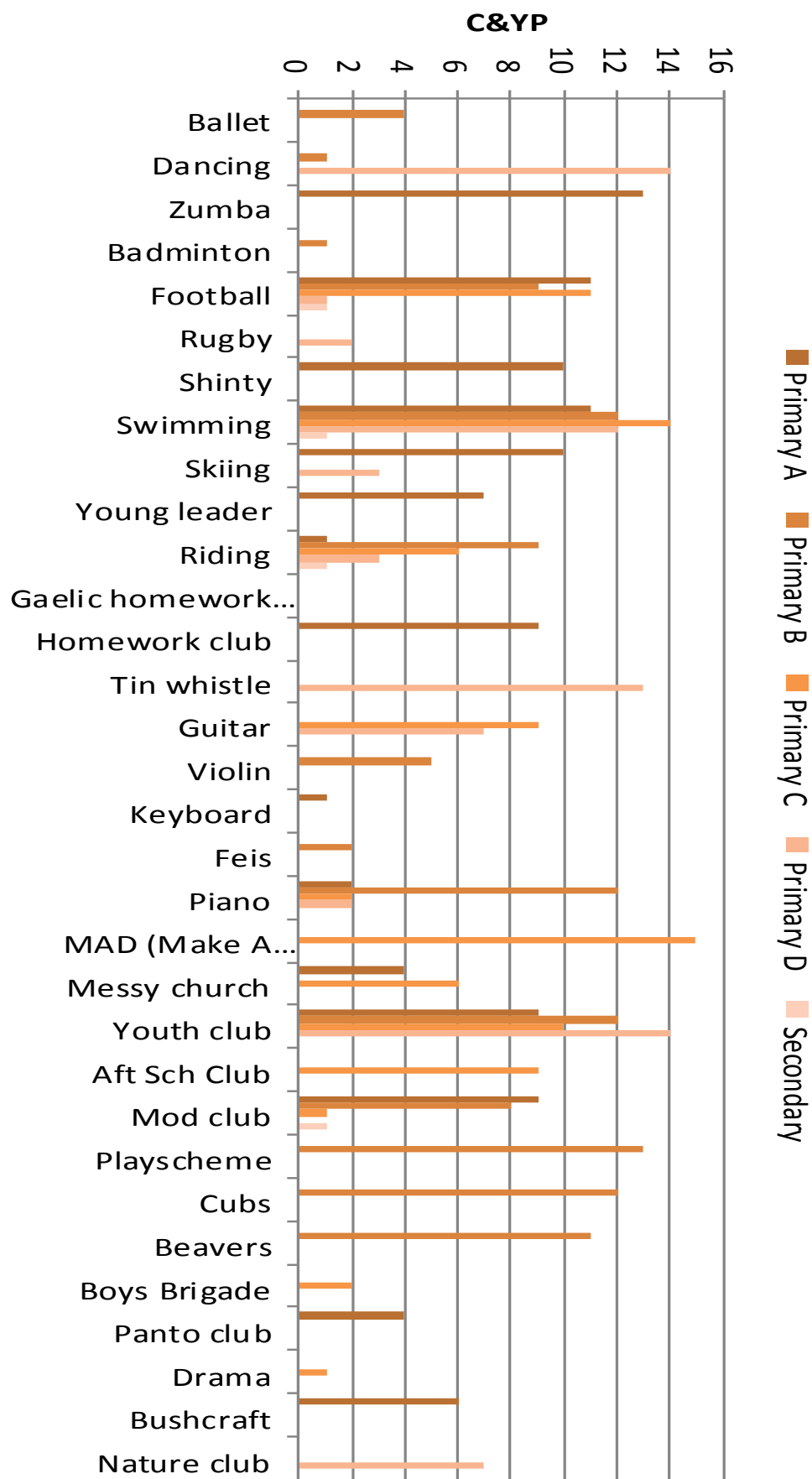
# Activity Range: Urban ASG continuation 1



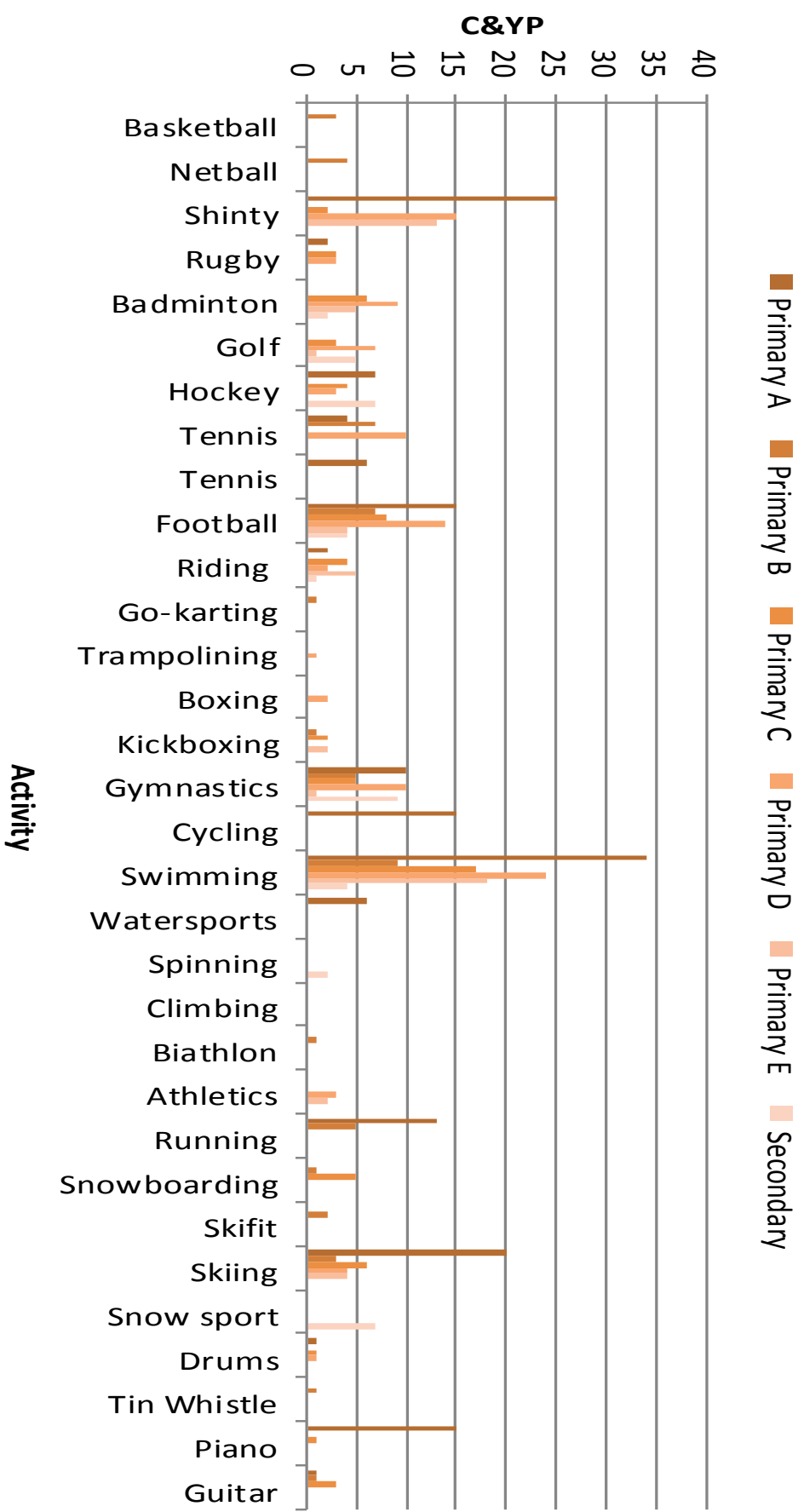
## Activity Range: Urban ASG continuation 2



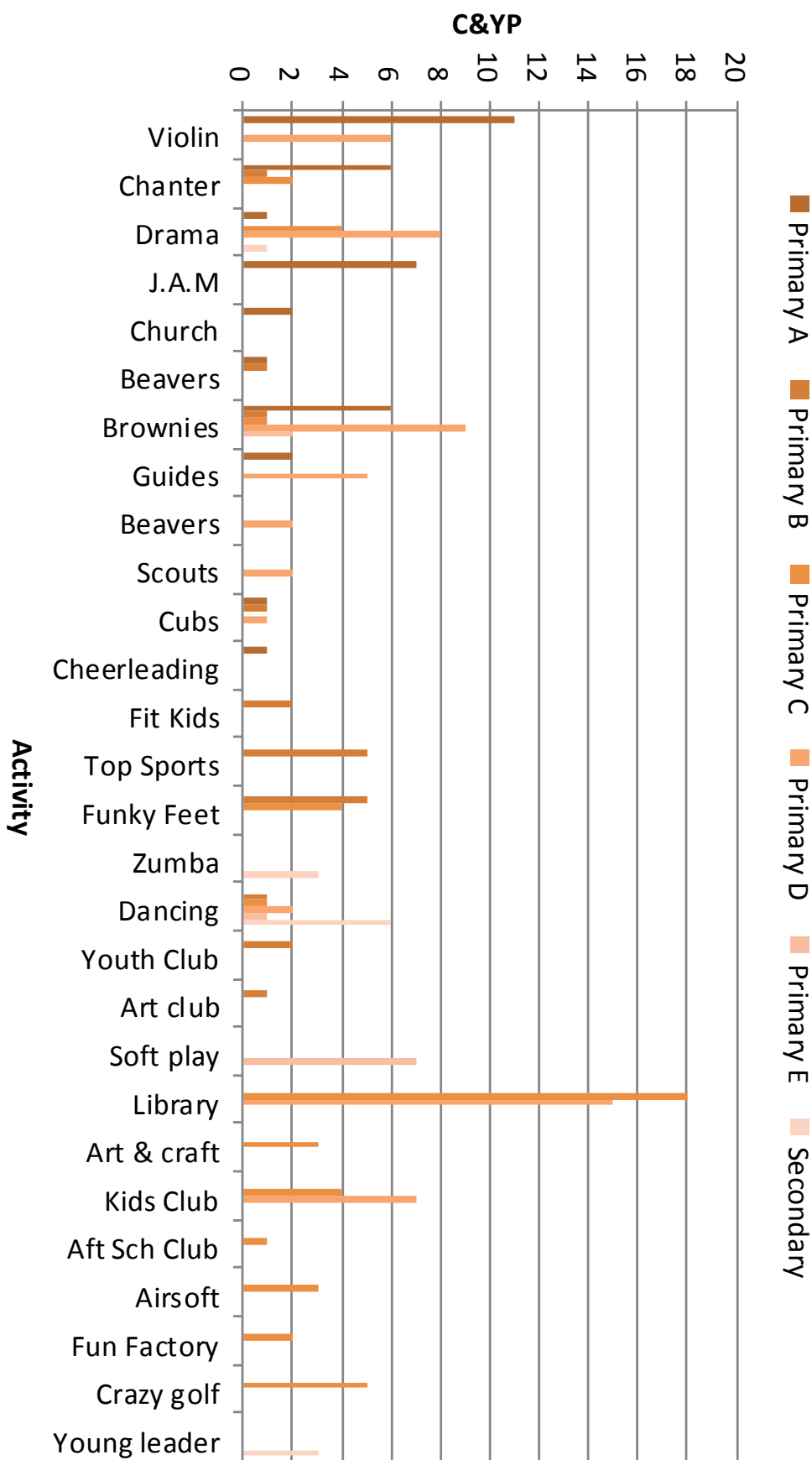
## Range of Activities: Sparse ASG



# Activity Range: Rural ASG



## Activity Range: Rural ASG continued



## Analysis of Needs Within the School Population Consulted

There are 1544 C&YP in the urban ASG; 185 were consulted – 12%

There are 940 C&YP in the rural ASG; 175 were consulted – 19%

There are 248 C&YP in the sparse ASG; 114 were consulted – 46%

(School Roll Statistics from

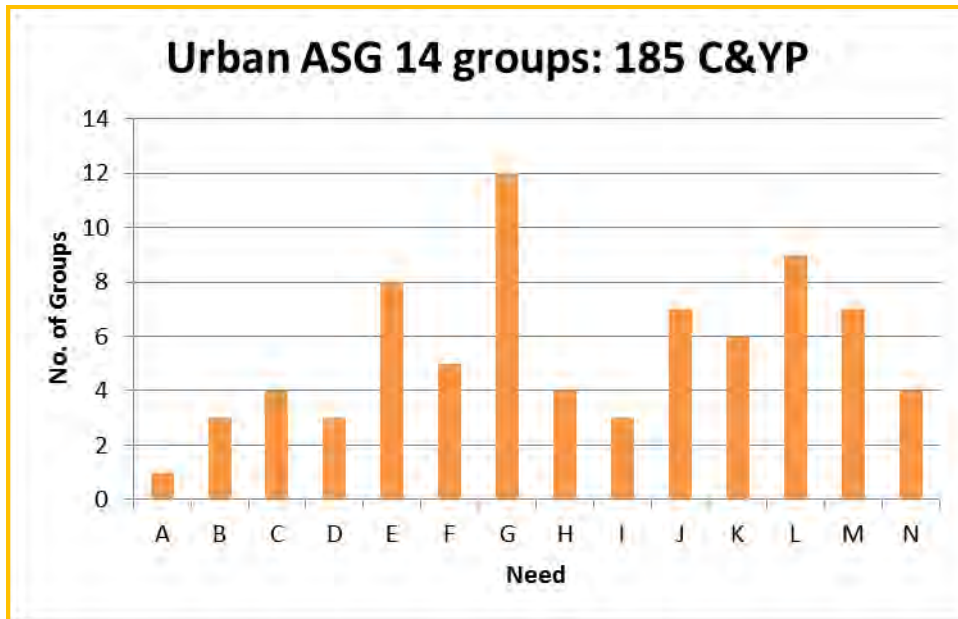
<http://www.highland.gov.uk/NR/rdonlyres/219A4AEC-F08B-44E9-897B-14AC9E210D5C/0/SchoolRolls1213NewAreas.pdf>)

The initial intention to collect information from the children and families about their needs was not possible as the needs questionnaire, originally with the consent form was not being completed. Head teachers or class teachers were therefore asked to fill in a generic needs questionnaire (Appendix 1 Page 60) The information gathered therefore represents only the needs that schools are aware of.

As it was not possible to collect data on the actual number of C&YP with needs but only of the needs represented within each group it can therefore be assumed that the data collected represents the minimum number of C&YP with the need.

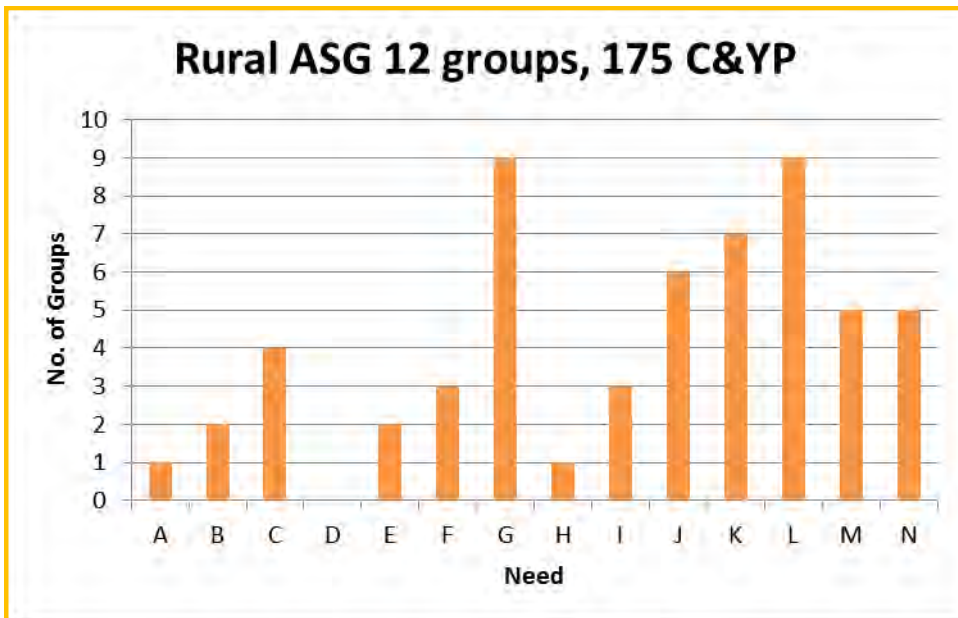
The key to the needs is in Appendix 2 Page 61



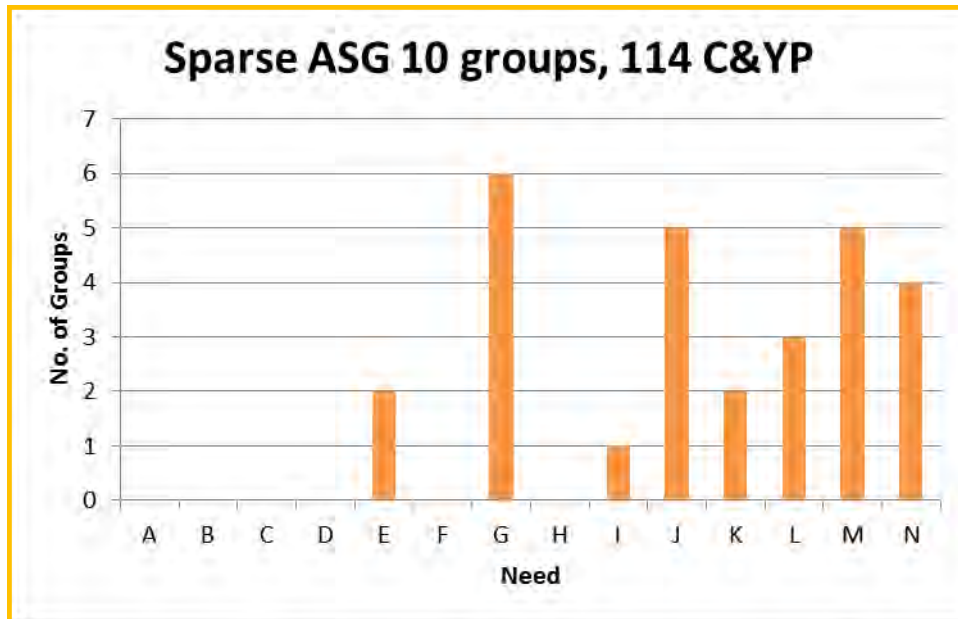


In the urban area the full range of needs was encountered in the general school population. The most commonly encountered need was G. – *someone the child loved in their family had died or left home*. This was encountered in 12 of the 14 groups.

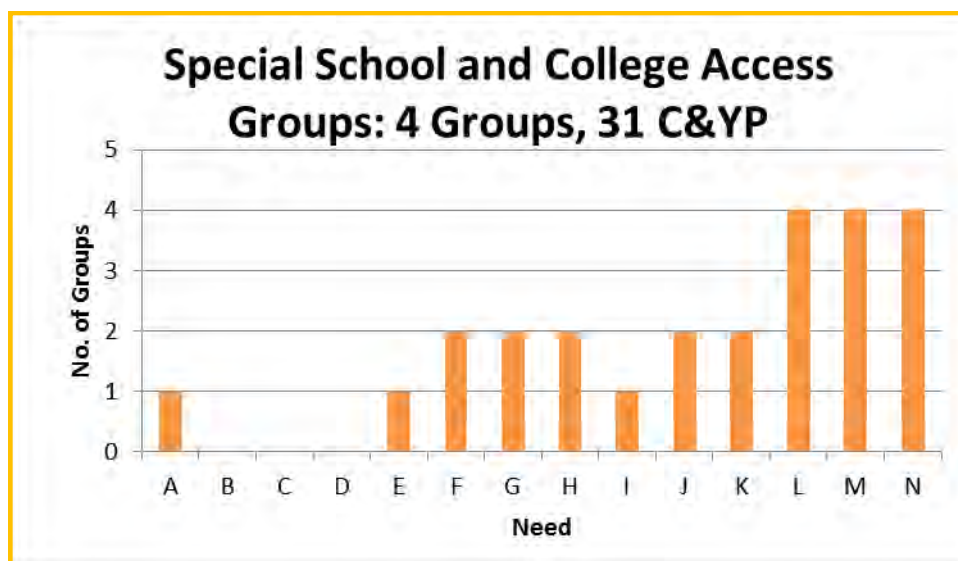
The need encountered the fewest, in one group, was A – *the child does not live with his/her family*



In the rural ASG the most commonly occurring need was again G - *someone the child loved in their family had died or left home* and L – *the child finds it harder than other children to learn things*, occurring in 9 groups each. D – *the child comes from a gypsy/traveller family* was not encountered at all.



In the sparse ASG, again G was the most commonly occurring need - *someone the child loved in their family had died or left home*, represented in 6 groups. The range of need present was much narrower with 6 of the needs not encountered at all.



The FE (Further Education) college and Special School were located in the same geographical area as the urban ASG and drew most of their students from the urban area. That the C&YP finds it more difficult than other C&YP to learn things, to talk and listen and to control their behaviour and actions was encountered in all groups. In these 31 C&YP B - *the child's family does not have a home of their own to live in*, C - *the child's family come form a country outside of Britain* and D - *the child comes form a gypsy/traveller family* were not present at all.





### **Feeling Included and Excluded Within the School Population Consulted**

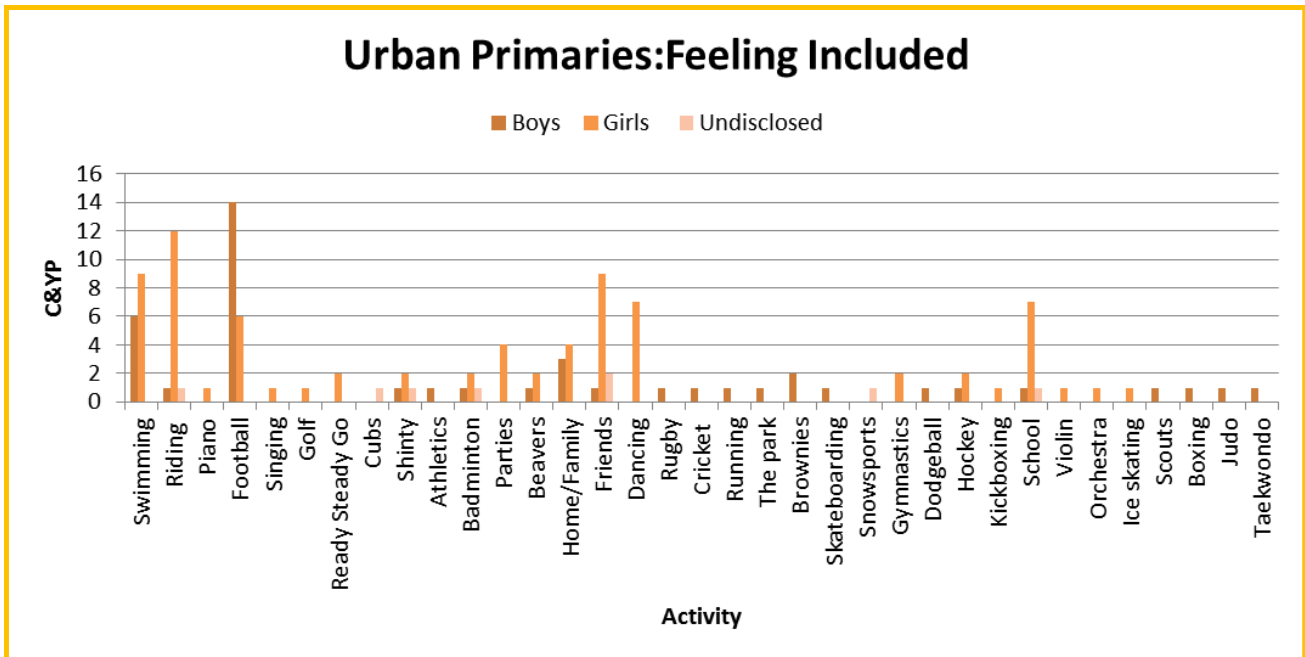
Following an activity to explore and refine their understanding of inclusion the C&YP were asked to think of a time when they had felt included and a time when they had felt excluded. The C&YP understood this in terms of feeling left out and joining in. They were asked to draw and/or write and the responses were transferred to charts for analysis.

The most common response for all 3 areas in both primary and secondary schools for feeling excluded was that they never felt excluded.

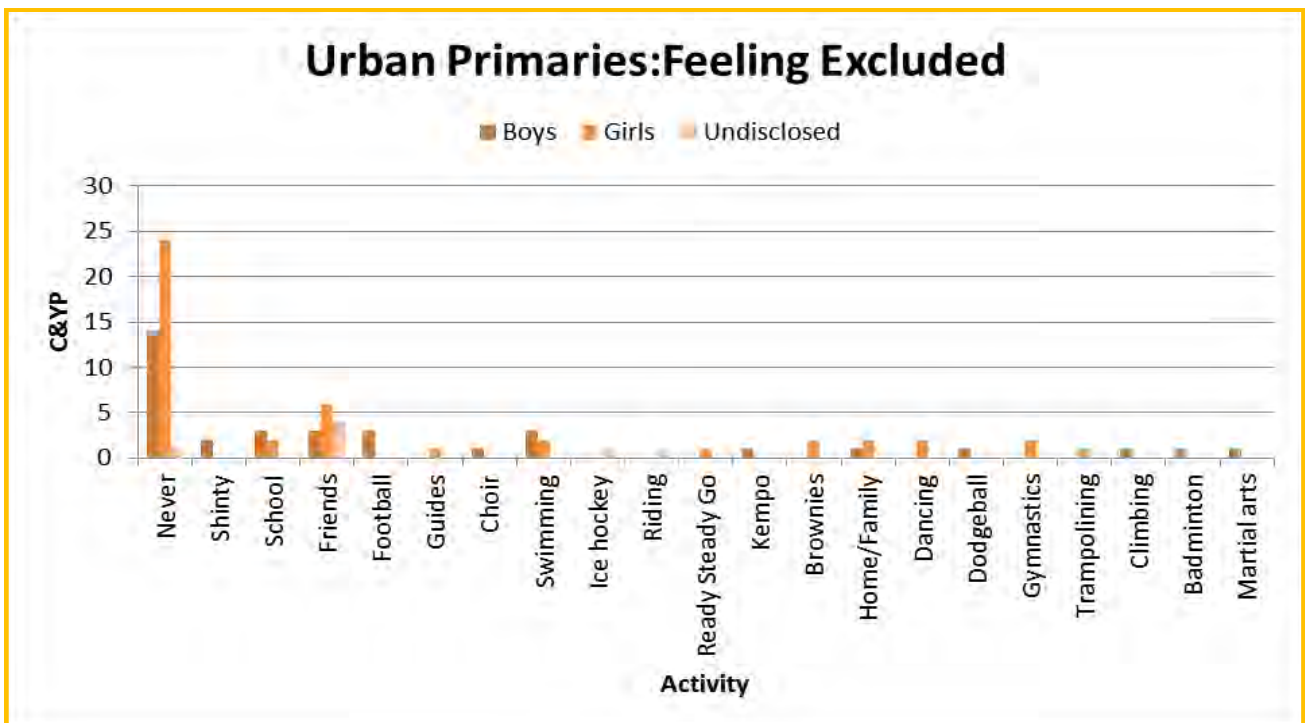
It will be noted that there were certain activities in which some children felt included whereas others felt excluded in the same activity, reflecting the individual child or YP's experience of the activity.

That friends and family are important can be seen from the charts, with the primary aged children frequently having a friends or family context for both feeling included and excluded. This was less noticeable with secondary aged YP though this may be a consequence of fewer of this age group in the sample.

## Urban ASG primary schools; 71B, 84G

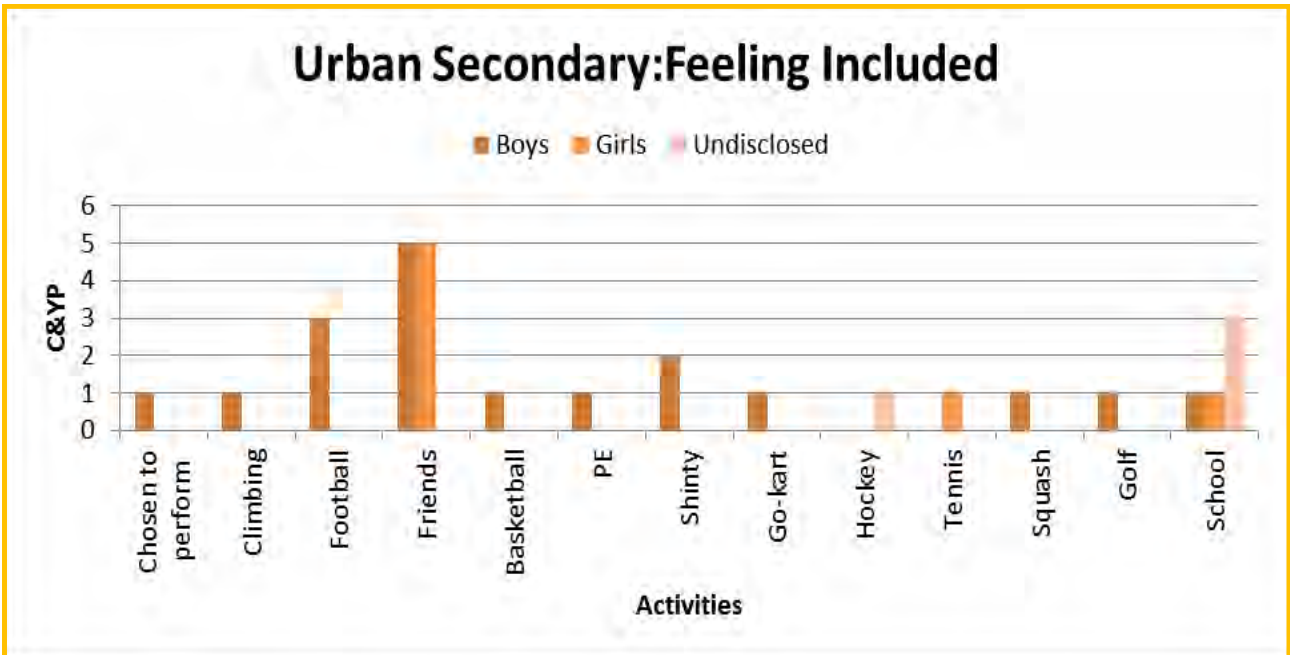


In the urban primaries boys and girls had an almost equal range of activities in which they felt included, (22 boys, 21 girls), though girls had a greater emphasis on friends and family, boys on sport.

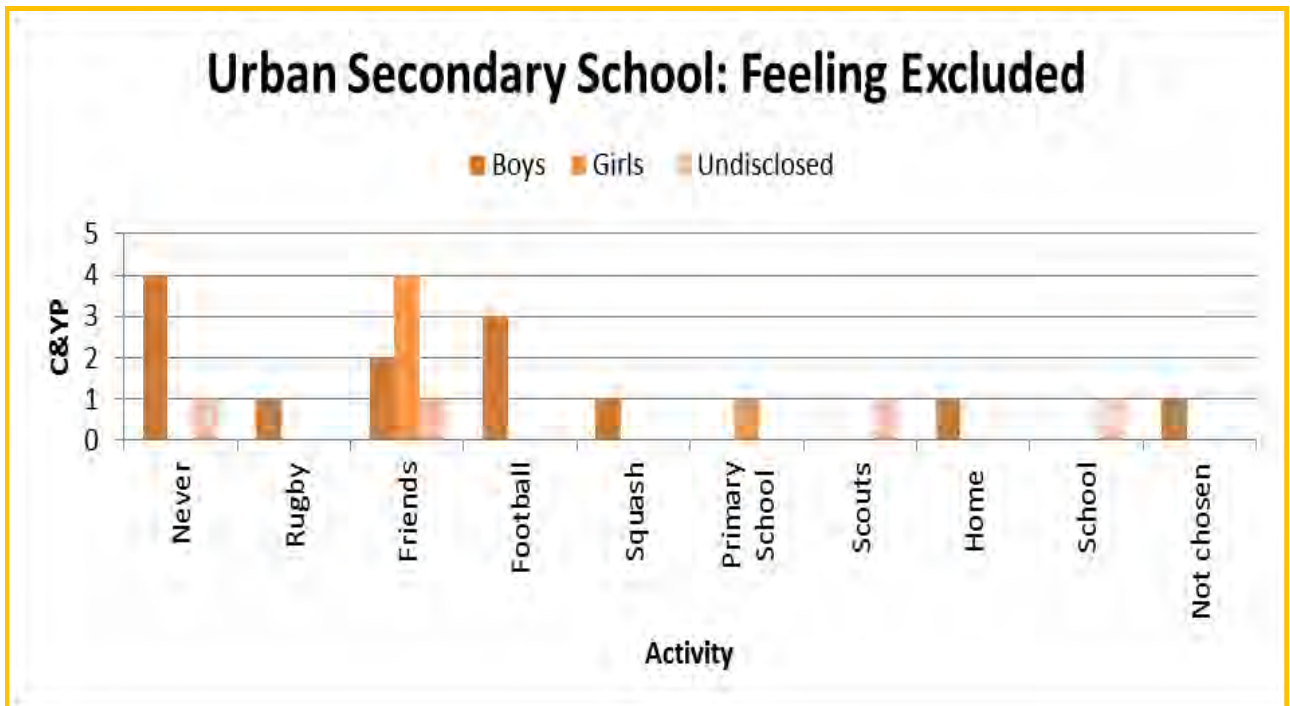


Of the urban primary children girls were more likely than boys to have never felt excluded ( 24 girls, 14 boys), and girls were more likely than boys to have felt excluded in family or friends context. There does not seem to be an activity where a large number of C&YP feel excluded.

Urban ASG secondary school; 19B, 11G

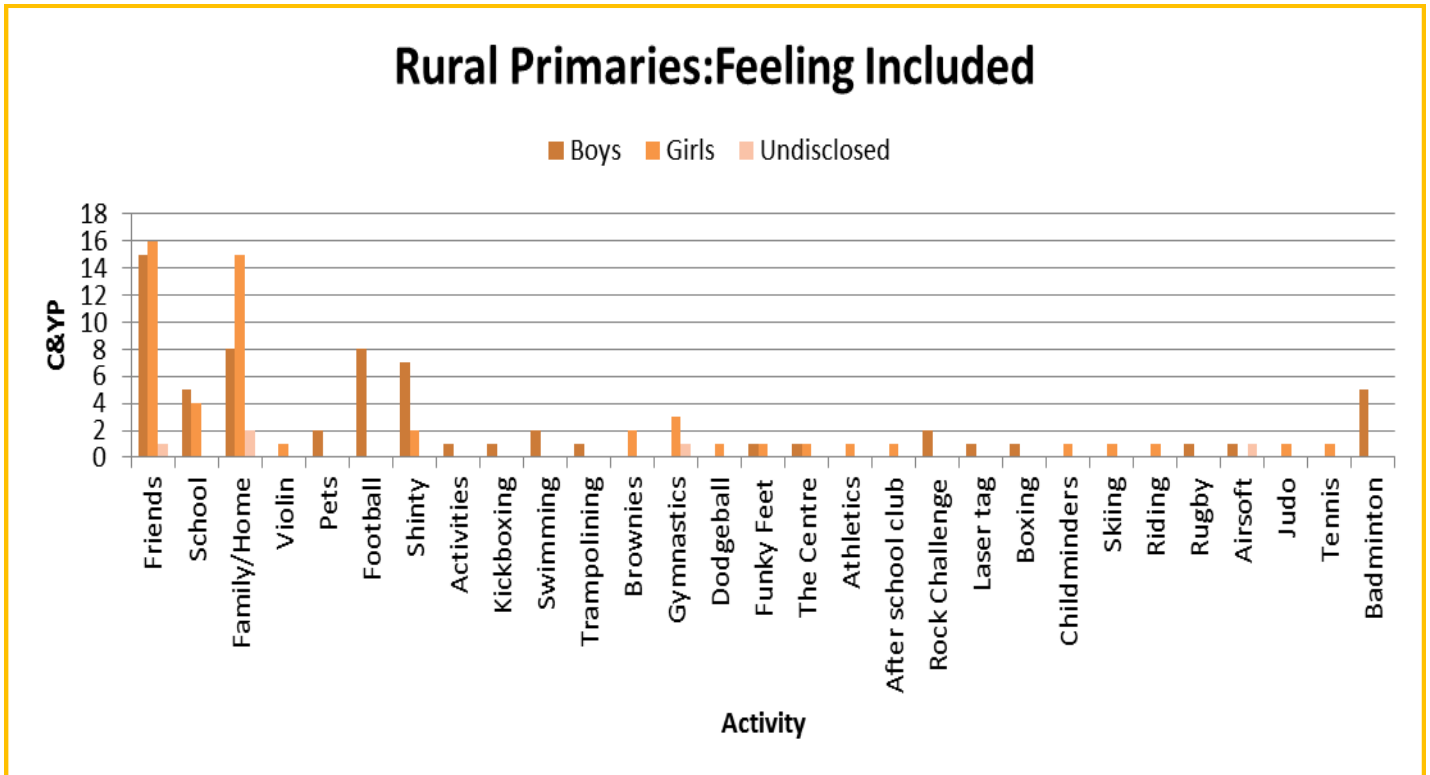


In the urban secondary pupils consulted equal numbers of boys and girls felt included in a friends context. There was only one girl who felt included in a sport context compared with 8 boys. The chart suggests that, overall there were more activities in which boys felt included than girls.

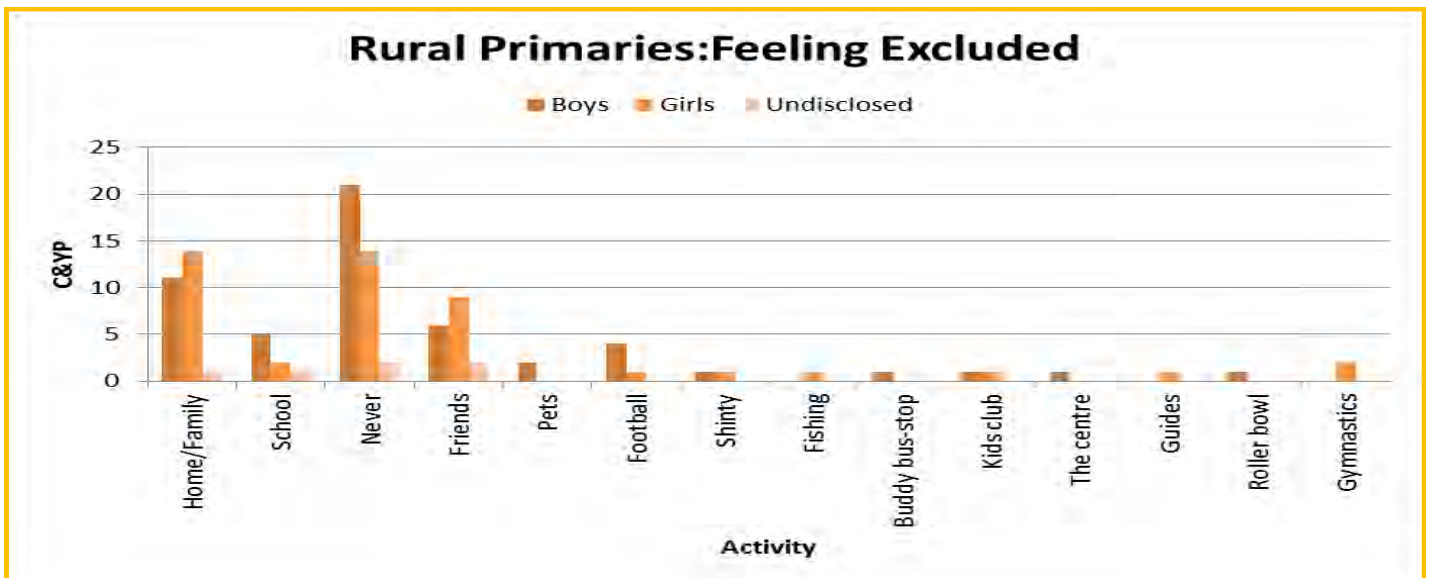


Of the urban secondary pupils boys were more likely than girls to have never felt excluded. Boys were more likely than girls to have been excluded in a sporting context, perhaps because they attend more sporting activities, similarly girls were more likely than boys to have been excluded in a friends context.

Rural ASG Primary Schools: 77B, 61

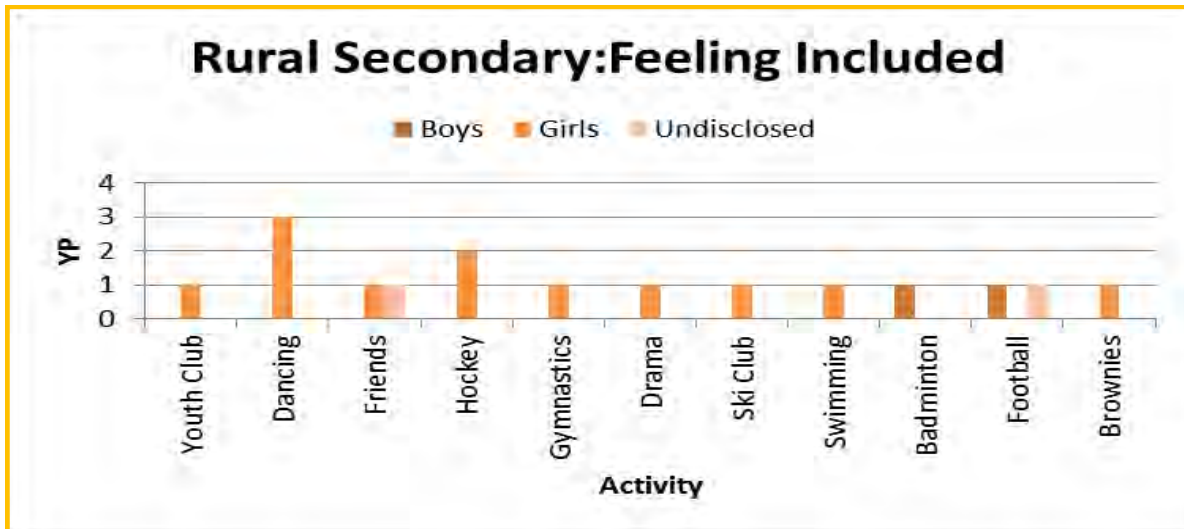


Boys had a greater range of sporting activities in which they felt included, whilst more girls felt included in a friends and family context than boys.

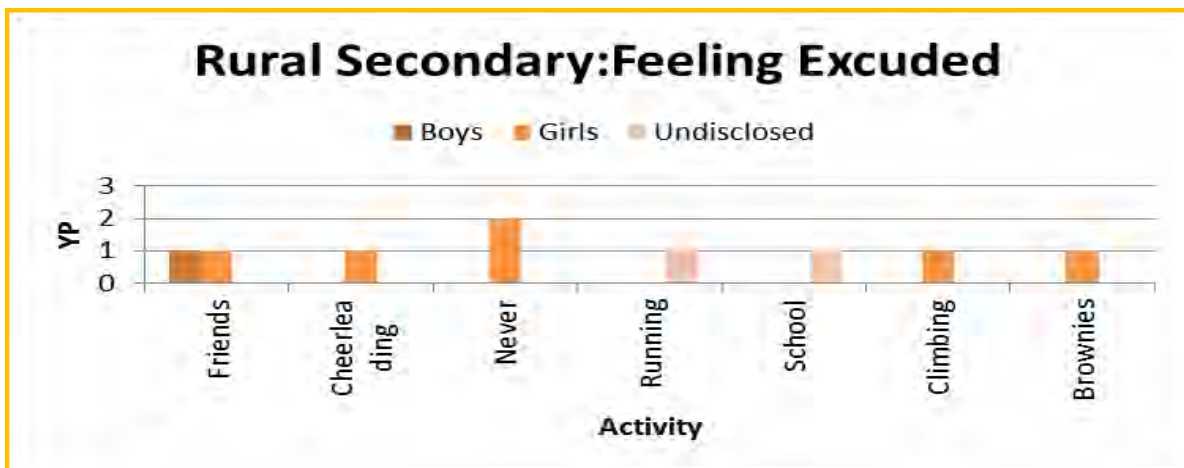


More boys than girls never felt excluded (21 girls, 14boys). More girls than boys felt excluded in a friends/family context.

Rural ASG Secondary Schools: 11B, 26G

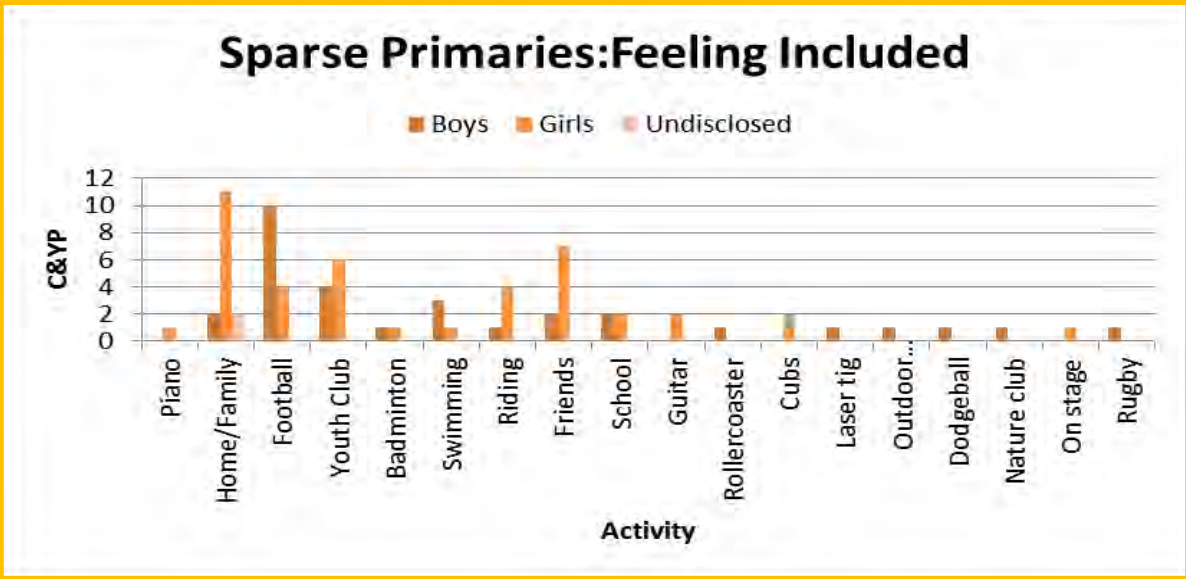


Boys only felt included in two categories, both sporting contexts. Girls had a much greater range of categories in which they felt included.

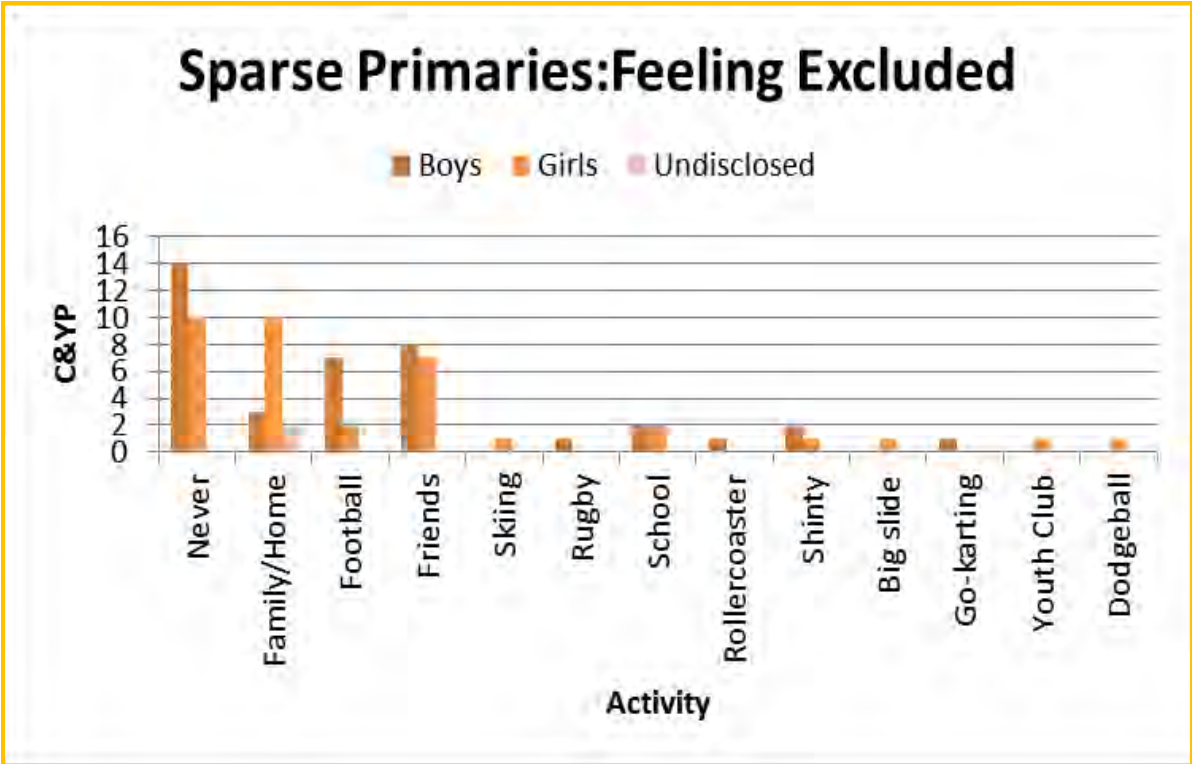


Boys did not feel excluded in any category other than friends. Girls had a greater range of categories in which they felt excluded. 2 girls had never felt excluded.

Sparse ASG Primary School: 50B, 53G



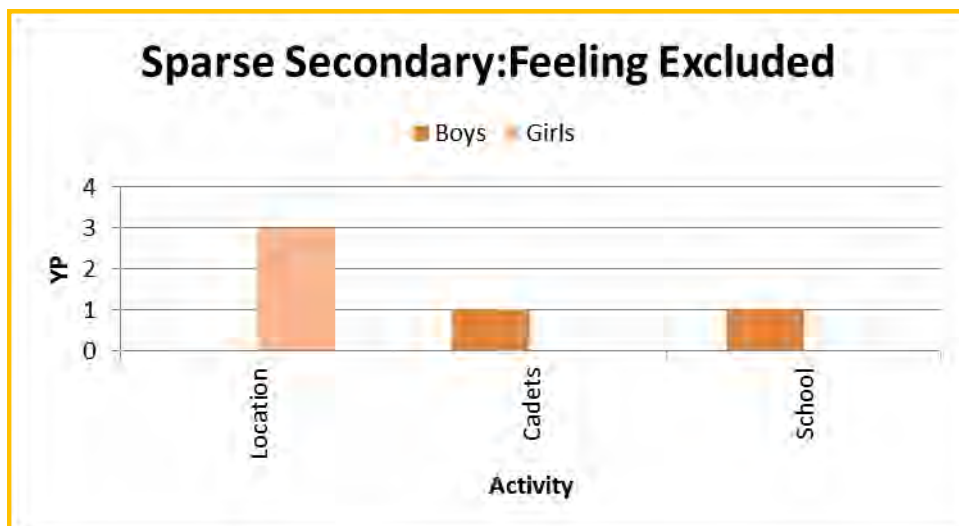
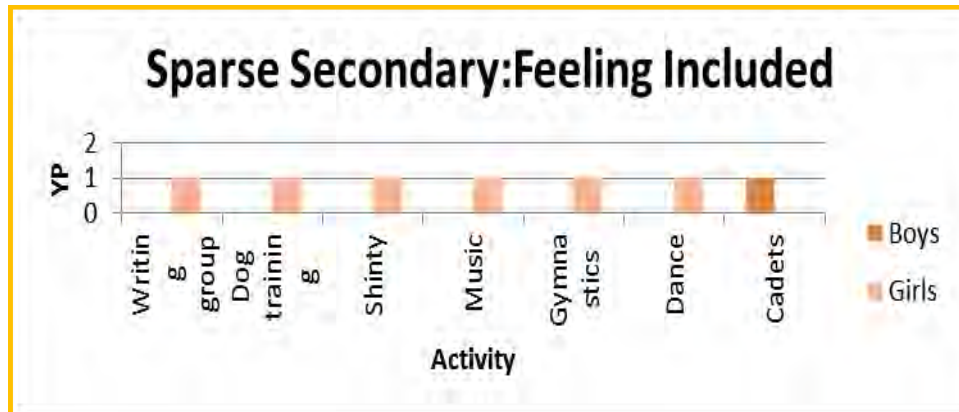
Girls were more likely than boys to cite a friends/family context for feeling included. (18 girls, 4 boys)



Boys were more likely than girls to have never felt excluded (14boys, 10 girls)

## Sparse Secondary ASG: 3B, 8G

The size of this sample and the number of responses make it difficult to draw any conclusions from it.



**Bad**

- Nothing is on in my village
- It costs too much
- Its too far away
- You need experience
- Its always sport
- no room on the bus!

Many C&YP had issues with structures that made them feel exposed or singled out e.g. being last to be picked for teams, and paradoxically the 'buddy bus stop' which was used by many schools to help children find company in the playground was seen as stigmatising. Their responses suggest that Inclusion is closely linked to general wellbeing and happiness with some children feeling that a life event e.g. the dog dying could increase the likelihood of being excluded. Responses also suggest that it is closely linked to confidence and self-esteem with many C&YP suggesting that not being competent at something, or having to play with older children led to feeling excluded. Being shown what to do and supported to improve, led to feeling included.



## Conclusion

It is heartening to see that it is evident that the C&YP, especially at primary age attend a huge range of activities, both in number and variety. There is a greater attendance at youth club and a much greater uptake of instrument teaching in the sparse area than in either the urban or rural areas. There is also a good uptake of activities organised by the ASCs in all three areas.

When considering where they feel included and excluded it can be seen that friends and family score high in both the included and excluded responses reflecting the importance of friends and family to the well-being of C&YP. It is also heartening to note that the most common response to feeling excluded was that of never having felt excluded.

There seems to be a correlation between feeling included/excluded and happiness and well being, self esteem and confidence.



## What Individual Children and Young People say about Inclusion

There were 10 individual C&YP with specific, identified needs who were consulted. Their needs included ASD, Tourette's Syndrome, obsessive compulsive disorder (OCD), mental health issues, eating disorder, young carers, visual impairment, looked after YP, sibling of a child with profound and multiple learning difficulties (PMLD).

The discussions ranged over topics of education/work and leisure activities, exploring the extent to which the C&YP feel included, the possible barriers to inclusion, what works well and what would improve inclusion. All names have been changed to ensure anonymity.

Views and experience of education were varied. Of the ten C&YP two had now left school, Jane (19 years) with visual impairment had attended normally and had been looking for work for 2 years. She felt that school had made her more resilient. She feels that she may have got better qualifications in specialist provision but...

*...It would have shut me off and shielded me from real life and that would not be healthy as you have to live in the real world.*

Lucy (17 years) has a diagnosis of ASD and had been out of school since S2 as she could not cope with the environment. On approaching 16 years she was told by the social worker that she would have to leave school.

Two were attending school normally. Jake, a 13 year old whose brother had PMLD reported that he loved school. The other was Michael a 15 year old boy with ASD who followed a normal attendance pattern at a special school, having had an abortive and distressing start to his educational life in a mainstream school.

Three were not attending school; sisters Sarah and Becky (aged 12 and 14) had a caring responsibility for their mother and had been withdrawn from school by her as a last resort, as they were being bullied. The other non-attender was 12 year old Rachel, who was awaiting a diagnosis of ASD, and attended only occasionally for a specific subject.

Three were attending on a part-time timetable, Mhairi aged 12 with ASD, Esther, aged 18 with Tourette's syndrome and Michelle aged 15 who was looked after by a foster carer. None of these YP felt that they could cope with more school than they were currently attending, with Michelle who is 'looked after' commenting that the part-time timetable was what had prevented her from being excluded more often.

There was a range of response to discussions about leisure activities with Jake (sibling of boy with profound needs) 'loving my sports', but not belonging to any clubs. He says he is very busy with his own activities and prefers to do his own thing with his friends (who were outside, waiting for him with a football, during our discussion). Some of the C&YP reported that they used to take part in leisure activities, but no longer felt able to. Esther was too tired due to an eating disorder, and Mhairi (ASD) had a variety of reasons for not attending organised activities but she enjoys playing at the park and on bikes with her 'best friends.' Michael (ASD) had a very full and active calendar attending a number of clubs and activities, with a balance of mainstream and specialist provision.

## **Barriers to Inclusion**

Environmental Barriers The busy sensory environment and the large numbers of other C&YP were the major barriers for all the ASD C&YP who are, or had been, in mainstream schools.

The C&YP who are on part-time timetables or have school placements out of their school catchment area find friendships and social opportunities more difficult to sustain.

Jane, who is visually impaired finds some settings e.g. the Aquadome too 'busy' and bright.

Michelle, who is in foster care, feels that the rural town in which she is in foster care is a barrier to inclusion as there are 'too many druggies' and nothing to do.

Structural Barriers The C&YP identified a number of structural barriers:-

Esther (Tourette's Syndrome) had been offered a conditional place at university dependent on completing a 10 week summer school; this requirement has not been made of other applicants. Esther feels that this is discriminatory and also starting so soon after school finishes (3 days) takes no account of the fatigue she experiences. 'Education' are slow to put alternatives in place for C&YP who are out of school. In the case of the young carers some of the school interventions which had been done with supportive intent had been counter to inclusion e.g. the CSW (children's service worker) taking Becky out of class to talk to her, though intended to be helpful had the effect of drawing attention to her.

Jane, who is visually impaired, found that the Job Centre does not hold literature in accessible formats and NHS accessible literature has to be requested and takes weeks to arrive. She finds there is a lack of support; her contact with counter staff at the Job Centre takes less than a minute. She can request an appointment with the Disability Officer but they are difficult to obtain. Her job seeker's diary has the same requirements as an able-bodied person; she feels that as it is more difficult to evidence job-seeking activity as a visually impaired person the requirement should be less so that she stands an equal chance of being included in the world of work.

Attitudinal Barriers There were some examples given of instances when YP had experienced what they perceived as negative attitudes. Many were around school staff being unsupportive and dismissive, or school policies being implemented with no allowance for individual needs and circumstances.

Sarah and Becky (young carers) felt that school staff were unsupportive of C&YP who reported bullying. Michelle, who is in foster care, is barred from social events at school because of 'stuff that happened earlier'. She feels that school are holding a

grudge and not giving her a chance.

Both Michelle and Lucy (ASD) had formed the view that SW could not be trusted to keep their word and gave examples.

Jane (visual impairment) feels that Job centre staff have a lack of empathy and flexibility.

## **What is good**

Seven of the ten C&YP said that friends were important; they mentioned friends being 'supportive' and 'really nice'. School friends seemed to feature most prominently and these friendships were often continued outside school.

The social worker is making the best progress in negotiating a school placement for Sarah and Becky (young carers)

Highland Community Care Forum's Young Carers' worker has been very supportive of Sarah and Becky and has provided them with social opportunities and they have appreciated the opportunity to make friends with others 'who are in the same situation and understand'.

Jake receives a service from CHAS at Home (Children's Hospice Association Scotland) as his brother has complex needs. He goes on outings once a month or so, but has more contact in the holidays or when his brother's health needs increase. CHAS also provides respite opportunities for the whole family so that Jake has time with his parents.

Esther has an alert card, to explain her Tourette's Syndrome, if necessary.

Jane has felt most comfortable at Haggeye (a forum for YP with vision loss) as others were in the same circumstances and all adaptations were in place; she says she felt really accepted. She had found her SDS (Skills Development Scotland) worker to be 'wonderful' and whatever was organised by him would have everything to meet her needs ready and in place in advance.

## **Conclusion**

Though the C&YP had a number of positive experiences to relate there were a number of barriers to their inclusion, particularly structural ones, mostly of an avoidable nature.

These YP had experienced varying levels of support and understanding. The ones who had had an early diagnosis at the beginning of their school life seemed to fare better than those for whom diagnosis came later, perhaps reflecting that their behaviour had an explanation, and that they had had their needs met from an early stage in their school life. For the C&YP who are either fully or partially out of school, particularly those with ASD the amount of support was not the critical factor it was the school environment that they could not cope with. The lack of any viable alternatives seriously compromises both the education and the inclusion of these YP who need solutions which will take account of their individual needs.

## What Schools say about Inclusion

Head teachers were asked to comment on inclusion within their schools by answering the basic questions of what contributes, and what barriers there are, to inclusion for their schools. These conversations were of necessity fairly brief as many of the head teachers had to make time within the consultation visit.

To explore the extent to which schools were able to include all children with additional need they were asked whether they had children on roll but not attending school. Of 16 primaries there were 3 positive responses representing 5 children; of the 3 secondary schools there were 2 positive responses representing 7/8 YP. Most of these 13 children were on part-time timetables with 3/4 attending 'The Bridge'.

### **What Contributes to Inclusion in Schools**

Attitudes – many head teachers cited attitudes as contributing positively to inclusion within their schools. Many were happy to report committed staff teams and supportive communities and gave high priority to engendering a positive, tolerant, inclusive school ethos, with measures in place to ensure that children had a voice. The more rural schools recognised their advantage in achieving this ethos as the children, families and community are typically close-knit and supportive. There were a number of examples of initiatives within schools to facilitate this ethos e.g. schools councils, various break-time and after-school clubs :- eco clubs, sport, craft, music, drama etc. with an emphasis on democracy, fairness and responsibility. There were also some 'buddying' initiatives for new pupils and for pupils who felt they needed it, with a playground 'buddy bus-stop' mentioned in a number of schools.

School environment – some of the schools were of recent build and head teachers reported that the easily accessible, well designed and attractive buildings had a positive effect on the ethos and atmosphere. One head teacher went so far as to say that the new school, along with its community facilities had reinvigorated the whole local community, made it feel valued and given it fresh enthusiasm and cohesion.

Transport was also mentioned by almost all schools with the availability and cost being cited. Schools recognised the immense value of the various community, private and statutory funding initiatives that were available, stating that any cuts to transport funding would be hugely detrimental to the inclusion of the pupils. Transport was seen as absolutely fundamental to inclusion; meaning that rurally isolated schools could organise joint events with other schools, support the curriculum with visits and the C&YP could take part as active members of both the school and the wider communities.

It is a common view that the smaller secondary schools would only be able to offer a restricted subject range, but the schools believe this is largely perception and are able to offer some subjects by arrangements with other providers e.g. Further Education Colleges.

There was also an example of a very small and sparsely located primary school being offered the opportunity to access local community education provision and older pupils had experienced woodwork.

Many schools gave examples of how certain activities were subsidised, some from community funding, to ensure that all pupils could access them. These activities were seen as important to both support the curriculum and to facilitate cohesion within the school community. They were also seen as important in allowing the less academic pupils to shine, bestowing benefits to self-esteem and confidence, essential to inclusion.

Access to external services and agencies and an appropriate number of support staff were cited as essential to supporting C&YP with additional needs, though there were some reservations about the processes and levels of bureaucracy needed to achieve this.

There were a number of schools, with gypsy/traveller children on roll whose needs have historically been difficult to meet due to the itinerant life-style. The prevalence of official encampments has seen much more consistent attendance, and the continuity of contact has resulted in much more trust. Schools report no inclusion issues, apart from occasional seasonal absences, but more trusting relationships have resulted in better communication and negotiation regarding this.

One primary school in the sparse area with a child with a specific syndrome categorised mainly by learning difficulty, felt that her inclusion was best served by supporting her in social and independence skills (e.g. using cutlery and toilet training) as her difficulty with these skills was setting her apart from her peers. The child joins in with class routines. Activities are differentiated where possible to ensure access for her.

### **What Barriers to Inclusion Exist For Schools**

Environmental Barriers - The school building was the most frequently mentioned barrier to inclusion, with some schools having a number of issues – poor repair, old buildings, unsuitable layouts, temporary buildings, rooms on different levels, sloping sites with numerous steps, lack of space generally, no large space e.g. hall.

Many of these issues are difficult or impossible for schools to overcome. Head teachers seemed to have established some creative solutions where possible, though these are always a compromise e.g. some had arrangements to use nearby village halls but expressed the view that this was not ideal logistically, particularly in inclement weather.

Rurality- The extreme rurality of some of the schools posed a barrier to inclusion with schools reporting that they felt that potential visitors e.g. peripatetic subject specialists, drama groups were put off by the journey. The logistics of even the provision of swimming are more fraught, with one school reporting that the P4-7 swimming lesson takes all day with the return journey taking the bulk of the time. There is also the difficulty of getting staff to cover absence in rural areas. This was an issue generally but compounded by the extreme rurality of the sparse area, making the provision of off-site activities e.g. swimming, where staff cover is required for the

children left in school, much more difficult.

Some activities, such as those organised by the ASCs are dependent on the capacity of the community to deliver, as volunteers. The perception was that volunteers are more difficult to recruit in sparse areas with long distances and more difficult working lives as factors, so reducing the provision of many activities e.g. Bikeability, to the schools serving sparse populations. The view was expressed that any activity whose evaluation is numerical 'goes for the easy hit' where larger numbers can be expected, and avoids sparse areas.

Transport – Schools, recognising the importance of the various transport funding streams to the inclusion of their students, both within school and community activities, were very fearful of the consequences if funding was reduced. Some small schools felt that, as they did not have buildings suitable to host visiting school groups, there was an even greater reliance on transport as they always had to be the visitor. The rural area (unlike the sparse area) did not have the benefit of the rural transport funding and this was keenly felt.



Structural barriers – Some schools felt that the impact of the presence of some of the children with additional needs on the other children (this in the context of 3 ASD P1-3s all in one small school) was disproportionate. These 3 children were included as much as possible and the school had a sensory and soft play area indoors and a small fenced outdoor area to try to meet their need to withdraw from the sensory overload of normal school life but there was, nevertheless, significant impact on the other children.

Access to IT was mentioned by secondary schools, with no wireless connection an issue for some. The restrictions of the Fujitsu contract mean that pupils' laptops cannot be connected to the server and dedicated software to meet specific needs has to be installed by Fujitsu, introducing layers of bureaucracy and delay.

Staffing – Staff numbers in smaller secondary schools meant that there was a smaller pool and narrower range of specialist staff and expertise, so that individual needs cannot always be quickly met. Though training was available it was sometimes difficult to find the more specialised training and there are also issues of time and availability in accessing training. Difficulties in getting staff cover for absences was also mentioned.

The feeling was expressed in the rural area that £ for £ urban areas were advantaged and that the rural area did not have the benefit of the extra funding that the sparse area benefited from, meaning that the rural area feels disadvantaged compared to both the urban and sparse areas.

It is feared that the increase in head teachers' teaching hours and the cuts in janitor and administration hours are going to increase the pressures on schools, particularly on head teacher time. This type of cut may cumulatively have a negative impact on inclusion in the long term, by forcing it to a lower priority on schools agendas.

Attitudinal Barriers – There was little mention of attitudinal barriers however there was a feeling in the sparse area that as YP grew older there was some despondency as to their prospects of achieving a positive after school destination. The school was trying to ameliorate this by creating more and extended work experience options.

## **Conclusion**

Head teachers seemed to see the positive ethos and staff attitudes as the most important factor in engendering an atmosphere of tolerance and inclusion where all children had a voice and there were a number of initiatives to support this.

Also considered to contribute to inclusion were a well-designed and attractive school environment, partnership working amongst small schools, access to external services, agencies and appropriate staff to support ASN and changed strategic policies supporting the attendance of itinerant groups, previously typically not attending. Alongside ethos and attitudes availability of transport was seen as absolutely fundamental allowing C&YP to take part as active members of both the school and wider community.

The school buildings were the barrier to inclusion most often cited by head teachers with rurality and the effects it has on extra-curricular activities, provision of staff cover, volunteers, also a major issue.

The effects of integration of some C&YP with ASN on the other children was also an issue that head teachers brought up.

Staff concerns of cover and the difficulties of maintaining a sufficient level of expertise in dealing with ASN across a small staff were mentioned.

The effects of budget cuts and the long-term effects on inclusion was causing concern and there was a perceived lack of equity with rural schools feeling that urban areas have the benefits of proximity and sparse areas had extra funding, leaving them feeling disadvantaged.

## What Parents say about inclusion

It was decided to consult parents as they may have a deeper insight into their own child's inclusion/exclusion; what a child may accept as the status quo a parent may have more information about and may even have protected their child from the effects of exclusion.

There were 3 parent/carer groups consulted (18 parent/carers) and 9 individual parent/carers representing a range of needs of their C&YP including ASD, ADHD (attention deficit and hyperactivity disorder), OCD, communication difficulties, Tourette's Syndrome, learning disability, physical disability, sensory disability, young carer, mental health issues, complex needs and covering the full pre-school to 19 age range. Parent/carer groups and individuals were identified in both the urban and rural areas, but the sparse area yielded only individual parent/carers. Parent/carers will henceforth be referred to as 'parents'.

### What works well

Parents feel that inclusion issues become more manifest as C&YP grow older and want to access with more choice and independence.

Parents felt that the 'buddy' system some schools operate, whereby a child with ASN is paired with another or an older child, worked well and ensured that the child had a 'friend' at unstructured times e.g. break.

They felt that it was particularly positive that some leisure facilities (e.g. Inverness Leisure) have programmes of orientation in which the C&YP can make visits to become accustomed to various aspects of the environment prior to attending. This was especially appreciated by families of C&YP with ASD, who regularly have to abort family trips when sensory pressures become unmanageable.

### Barriers to Inclusion

Environmental Barriers It was felt that though there have been significant improvements in accessibility in the recent past there is still a way to go.

Parents reported that the mainstream school environment was a huge issue for C&YP with ASD; with issues of sensory and social overload being paramount. Responses of schools and services to this vary, with some parents experiencing understanding and willingness to be adaptive and supportive to try to maintain engagement of the C&YP. Other parents have experienced cumulative difficulties, even hostility and lack of resolution resulting in disengagement of the C&YP, a situation from which parents feel it is difficult to return to full attendance.

There were a number of C&YP (mostly with ASD) on part-time timetables for whom alternatives to mainstream school were not available or not offered. In many instances the parents were in agreement with the part-time attendance as they felt their C&YP would not cope with full-time, though there were reports of parents being rung to collect their child immediately as there was insufficient support. Many parents of these C&YP felt particular despair that mainstream school was not the right place for their children, but acknowledged that special school was not either.



Schools that require modifications to meet a particular child's needs often do not have them in place in time for the child starting to attend .

Some parents reported issues with changing facilities; communal facilities being a barrier for C&YP with ASD and a changing room designated 'disabled' was seen as stigmatising.

There were a number of issues with public parks, many of which required only a bit of thought at planning stage. Barriers include steps on climbing equipment often steep with widely spaced treads, play parks not enclosed (not suitable for ASD), en-



closed play parks with gates too narrow for wheelchairs, disabled swing with no straps (there is a 'phone number to ring to access the straps), outdoor musical instruments (potentially some of the most disabled – friendly equipment) at the top of a hill, the ledge retaining a safety surface too high for disabled access.

In Inverness parents report a general lack of facilities suitable for use by disabled children.

Personal care is difficult as many facilities only have a pull-down changing mat which is not suitable for changing anyone larger than a toddler. It is felt that a plinth, as exists at Eden Court Theatre, is more inclusive as it can be used by both babies and older C&YP.

There are issues with lifts not being big enough for large wheelchairs and buttons not always accessible.

Though shop doorways are usually fine many shop displays break up the internal space such that they are impossible to negotiate with a wheelchair, and many have children's wear at the back.

Structural Barriers Some parents, particularly those whose C&YP have ASD, felt that inclusion in mainstream was adhered to even when it clearly does not benefit the child, leading to increased anxiety, and ultimately school refusal, from which point it is very difficult to resume attendance. The net outcome of enforcing mainstream inclusion per se is one of exclusion and of exacerbating a child/YP's disability.

Some parents felt that there was an unwillingness of services to try personalised and creative solutions e.g. spilt placements and an unwillingness to listen to the parent's view of what would work for their child/YP.

There was a feeling that measures are put in place to manage crisis which, had they been put in place earlier, would have averted crisis.

There is sometimes lack of communication within schools and they 'throw surprises' or mismanage measures that have been agreed for the child, with not all staff being aware of or understanding a child/YP's needs.



Some parents felt that services still fail to see the child's needs within the context of the family and try to deal with issues in isolation, with services still operating independently and not communicating. This was apparent in an example where a parent had support needs due to her medical condition feels that all SW contact comes back to the YP's school as the lead professional. She felt that the impact of her needs on the family and of the YP's needs on her is not being acknowledged; the girfec model of seeing the YP's and family needs holistically is not being applied.

Respite was an issue for some, particularly for those families living some distance from 'The Orchard' (respite unit). There was a perceived lack of flexibility over alternative respite options. Withdrawal of transport means that some families have to transport their child there on a Saturday and back on a Sunday. For some the distances and time involved in the round trips mean that as much as 12 hours of their 2 day respite was spent transporting their child. Some parents expressed the view C&YP enjoyed social interaction with peers at the Orchard. Where family based respite is used no children are present and YP are denied the opportunity to be included with their peer group.

Parents reported that out of school clubs dedicated to C&YP with ASN had very long waiting lists and summer play schemes, where they were available, had to restrict access for C&YP with additional needs.

Lack of information became apparent whilst talking with parent groups as some individual parents were not aware of other options available for short breaks, childcare, local provision, Family Fund, etc whilst others were. There was also a lack of understanding of social services structure leading to some of the group being unaware of how to access assessments and support. There is a perception by parents that some information is deliberately withheld by services.

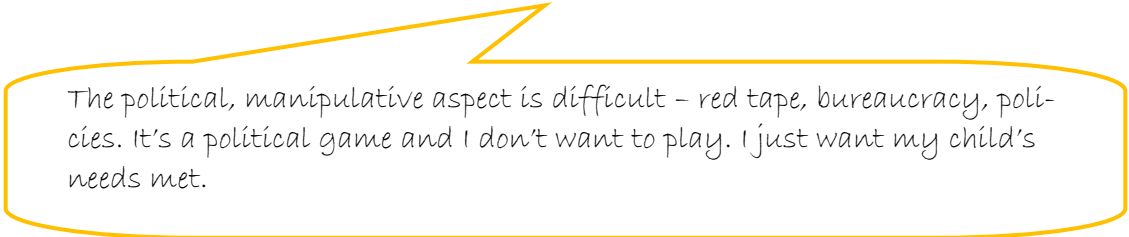
Some parents had experienced staff issues – with the lack of consistency resulting from a high turnover and perceived shortages being cited in some health services e.g. Paediatric Consultant and Occupational Therapy.

Funding applications are felt to be too lengthy, complicated and intrusive. One parent commented how difficult it is to have to revisit all the negative aspects of her child's condition in order to fill in the DLA form when ordinarily the way she copes is by focusing on the positives - and it takes a week to fill it in.

Training was seen as an issue by the parents and though they lauded volunteers within organisations they perceived a lack of training and expertise, particularly in managing bullying and challenging behaviour. Some parents felt that schools could make more effort to take advantage of opportunities to understand how specific conditions dictate a child's needs.

Meetings were seen as detrimental to progressing a child's inclusion in that they took so long to reach a productive solution with numerous examples of negative experiences being given. During a morning discussion with one group of parents one mother actually received a phone call inviting her to a meeting that very afternoon.

One parent commented that the Child's Plan process had been very positive with everyone agreeing, but she felt that it didn't matter what support was put in place in school her child could not cope with the 200 other children.



*The political, manipulative aspect is difficult – red tape, bureaucracy, policies. It's a political game and I don't want to play. I just want my child's needs met.*

Transport evoked the strongest views, with examples in both school and family contexts. There were examples of lack of vehicles suitable for transporting C&YP in wheelchairs, safety issues of wheelchairs and C&YP not being securely restrained, school taxis that toot and drive off without giving enough time for the child to emerge from the house. Transport arrangements seem to take little account of a child's individual needs, with examples of children with ASD being transported in a way that they found very distressing, with circuitous routes and numerous pick-ups. One parent stated that this anxious start to a day would have repercussions for the entire day and the cumulative effect was a negative attitude to school which became entrenched over years and was directly attributable to the journey.

## Attitudinal Barriers

*People (within services) don't realise what a huge consequence an action or lack of action can have for a child... some don't know, they don't know that they don't know, and they don't care.*

Many of the parents acknowledged the merits of much of the support they received from services and understood that professionals in the field had a difficult job. However most qualified it by giving examples of when their experience had been counter-productive in the quest for inclusion. One stated that she had had to 'go off my head' before she got the service her children need.

Inclusion is not just dependent on support but on ethos—it seems to be most successful in schools and organisations with, as one parent stated

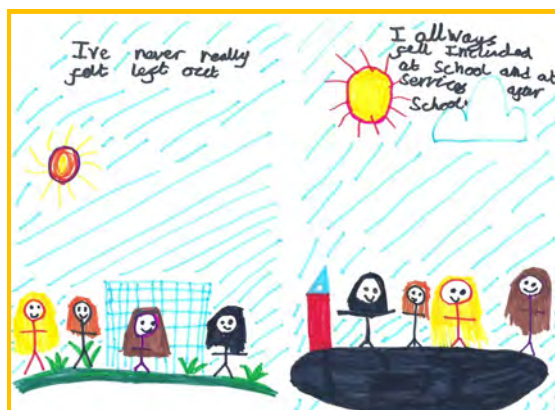
*...an ethos that is inclusive, welcoming, warm and encouraging and thus the YP themselves have been incredibly supportive (of the YP with ASN) because these attitudes have been instilled in them by the staff.*

Poor awareness of disability by parents of other children was highlighted as an issue, with some parents being seen as prejudiced and judgemental. If this is not challenged it impacts on a child's inclusion and also has implications as the parents role-model attitudes for their own children, resulting in a cycle of societal discrimination which is difficult to break. Sometimes the 'hidden' nature of certain disabilities results in the assumption that the child is 'naughty' or that parenting skills are lacking.

The attitudes of professionals were seen as very variable with parents giving examples of poor communication, lack of skills in dealing with behaviours associated with conditions, lack of understanding and of empathy. There is a belief that though many professionals are given basic disability awareness training, more advanced/specialised training is not widely available or taken up. Professionals and group leaders often generalise and assume that the child conforms to the label and are reluctant to plan for and respond to the child's individual needs.

Parents perceive that they are not listened to, that the considerable expertise gained by living with their child's disability is not respected or that they are not believed. Parents of some autistic children report that the child makes huge efforts to conform and fit in in mainstream school and the strain of maintaining this effort in an environment outside their comfort zone results in an outpouring of extreme and challenging behaviour when they are back in the security of their own home and family. This

seems to be universally dismissed by professionals when assessing the child's needs.



## Conclusion

Parents felt that there have been improvements in access in the recent past and that environmental barriers were relatively minor. Whilst there were some positives parents also gave a number of negative examples. The negatives would, for the most part, be avoided completely if the views of the 'experts', the service users and their families, were sought at design stage. For C&YP with physical disability the major issue was personal care. Most of the issues were of the suitability of settings, particularly mainstream school for C&YP with ASD, with parents feeling that no matter what support was put in place these C&YP could not cope with the sensory and social elements.

Many of the structural barriers were around communication issues - poor communication within and between organisations, meetings, lack of information, disregard of parents' views. Lack of flexibility and availability of respite and out of school provision was commented on and transport evoked strong words. Staff shortages, lack of consistency of staff and levels of training and expertise were all issues raised.

There was a strongly held view that there was a determination at strategic level to enforce a policy of inclusion for all, even when it was obvious that it was not benefiting the C&YP, and that schools have to 'make the best of a bad job'. Parents appreciate the services provided by most professionals with whom they deal. However it became clear that, as with other HCF reports (Recipe for Young Parenthood 2012, and How's Your Journey 2012), the attitudes of professionals can be very variable. This is particularly important with those who lead groups because attitudes which they are modelling to the group affect the ethos and the level of acceptance and support that the group offers.

*I'm not asking for miracles or ridiculous money. I'm looking to have children whose lives are hugely difficult to be made less so - just basic human rights met. The lengths you have to go to, to get basic human rights is mind-blowing.*

## What Providers say about Inclusion

During this consultation 23 people, of varying levels of status and strategic influence, were consulted within provider organisations.

The conversations had common themes, to explore providers' perception of the barriers to inclusion that they felt affected their provision. There were also discussions about the range of C&YP who made use of their provision and their arrangements to support YP with ASN who may attend.

Many organisations take steps to identify groups who are under-represented in their membership and try to redress this. Specific provision for C&YP with ASN was endorsed in certain circumstances (e.g. sports) where the C&YP's confidence and self-esteem would suffer from comparison in mainstream.

Those who hosted other groups within their building or employed external providers accepted that they had some responsibility for ensuring that this secondary provision was inclusive.

There seemed to be a high level of awareness by all providers of the issues. Most organisations seemed to have robust policies in place and many have someone in their organisation within whose remit was the responsibility for ensuring that inclusion was embedded in practice, and indeed many commented that it was a thread that ran through all their policies and practice.

There was a high level of consensus that, as one put it,

*'it is our responsibility to be accessible, not the responsibility of the visitor to adapt'. "*

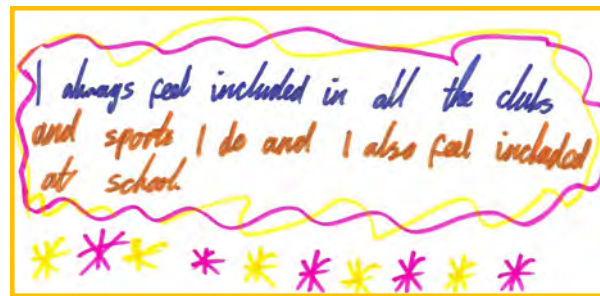
The challenge is to see whether this comprehensive awareness translates into practice.

### **Barriers to Inclusion**

Environmental Barriers The perception was that there are fewer issues as buildings become DDA compliant, either during initial building works or by up-grading. Where there are problems of accessibility they seem to be in multi-use premises where the organisation is just one of many user-groups with no real control over the building. For some voluntary organisations premises were expensive to obtain and/or maintain and the focus has to be on establishing provision within existing buildings e.g. schools. Though some schools do not have facilities that are compatible with the

range of uses required e.g. some rural schools do not have a hall and it is therefore difficult for user groups to offer sporting activities.

Rural isolation was thought by some providers not to be the barrier expected as rural communities are often small and close-knit and supportive of their own. YP from rural communities were thought to encounter more problems with social exclusion when they leave the support and acceptance of the school and local community. Some pan-Highland organisations have policies of focusing new provision or out-reach work in more rural areas and they perceive that this results in more equity.



Location was a difficulty for those providing a peripatetic service in sparse areas e.g. music tuition, though they have been flexible in their solutions to minimise its impact as a barrier.

Lack of authorised encampments was seen as a barrier to inclusion for gypsy/travellers as the consequent mobility affected their ability to access education and appointments. The resultant unauthorised encampments also give rise to the kind of selective and negative publicity which reinforces prejudice and stereotypical views and makes social exclusion more likely.

Lack of large venues capable of accommodating YP with physical disabilities in residential events alongside their able-bodied peers was seen as a barrier to their taking part in conferences etc and thus being able to access information and express their view e.g. at HYV conferences.

In one building that was subject to a public/private partnership arrangement there were perceived to be structural constraints on use as every space has to be booked, costed and paid for. In another the décor of the dining room was in the corporate colours of the company that held the catering contract and was challenging for the YP with ASD.

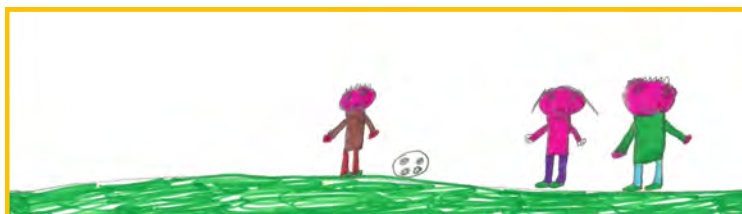
Capacity of venues was an issue in all 3 areas with community facilities being booked to the extent that it was difficult to identify spare timetable slots in order to increase provision.

Providers in the sparse area reported that their extreme rurality and sparse population make transport the biggest barrier to inclusion. Without the rural transport funding the picture would be very bleak for inclusion, with C&YP unable to access activities at all. There is also an issue that out-of-area providers are perceived to be unable/unwilling to make the journey. Rurality also means that costs are higher as the

transport cost and travelling time are factored in. Providers in the rural area also reported issues with rurality, particularly transport as they don't have the benefit of rural transport funding and it is difficult to co-ordinate activity times with public transport timetables.

Structural Barriers Financial—financial issues associated with inclusion were common to many of the organisations, and though there was little commonality in the nature of the specific issues cited, many of the organisations recognised financial need of the C&YP and their families as a significant barrier to taking part and to social inclusion generally. There were examples of differential pricing structures to include carers, and of a willingness to waive or subsidise charges to facilitate inclusion.

Some were concerned that the introduction of SDS (self directed support) may have an impact on quality as they felt there was a lack of clarity as to how quality (training, PVG [protection of vulnerable groups] checks etc) was going to be managed and monitored.



Time — inclusion of C&YP who perhaps need individual support was seen as leading to time issues for providers, impacting on capacity as staff time was allocated to give individual support.

Some providers felt that they were so busy that they were unable to be proactive in attracting YP with additional needs to their provision and relied on the YP making the approach.

Time can be a significant issue in early years settings. They are often the first provider to identify a need in a child or family and to initiate intervention. During the wait for partner agencies to acknowledge the need and support measures to be put in place the setting has to cope alone, with a consequent loss of quality as staff direct their efforts to the child and family's need. This has a cumulative effect on the other children, their families and the staff, and settings can easily find themselves in a downward spiral leading to a difficult operational situation. As children are in early years settings for a comparatively short time they may even move on before support is in place, so the process is delayed, increasing the feelings of exclusion for the child and family.

Time is also an issue for Young Carers who lack the time away from their caring commitments in order to avail themselves of the social, emotional and educational opportunities necessary for their healthy development and realisation of their potential.

Volunteers— For those organisations whose delivery is dependant on volunteers ease of recruitment can be a problem, with one provider reporting that paradoxically this is more difficult in urban areas than in rural ones, perhaps because volunteers commonly have a vested interest in the provision or the community which is easier to express in a rural area where people generally know each other and know what is available. Though volunteers are a much valued resource providers feel



that they often do not have the time to train to gain skills in working with C&YP with additional needs and providers are therefore reluctant to impose this requirement on them. This can reduce the capacity of the provider to meet the needs of C&YP with ASN.

**Health and Safety**—Some providers, particularly those whose programmes offer physical/sporting activity, report that there is a perception that the risks associated with offering these programmes to disabled CYP are greater than to the general population. They acknowledge that this is largely perception and that risks can usually be managed by adaptation. However some organisations felt that this perceived risk could be a barrier to inclusion as insurance companies are generally very risk-averse.

**Transition**—providers who work with YP during this phase of their lives reported that limited and late interventions from adult social work were a huge barrier to the vulnerable YP with whom they worked. To the extent that they felt that the sustained and comprehensive work that had been done by them to prepare the YP for adult life was negated by lack of support for the YP and their family once they had left their provision; destinations often break down with consequent loss of confidence and diminishing prospects of social inclusion. One commented that a successful transition to adult services depends largely on having parents with enough assertiveness and energy to be able to secure the package they are entitled to.

**Communication**—sensitivity of issues can sometimes a barrier to inclusion. In early years when the setting is the first agency to have concerns about the child it is very difficult and delicate to broach this with parents (who may not even suspect that their child has ASN) in a way that recognises the need for urgency of initiating the involvement of other agencies and support.

Some providers report that parents' reluctance (possibly through fear that their child will not be enrolled into the group) to disclose the fact that their child has additional needs can be a barrier; the organisation, not realising the child has ASN, is unable to put measures in place to meet the child's needs until those needs become apparent to the setting.

Providers acknowledged their responsibility to ensure that the C&YP were able to exercise their right to participation and some method of collecting feedback from service users or involving them in planning of programmes seemed to be almost universal.

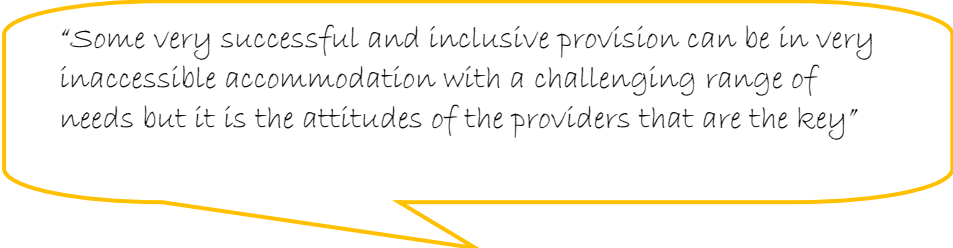
**Training**— Training of staff is seen as a barrier by those organisations that employ a large number of staff in order to meet the needs of their high-tariff client group. The turnover of staff means that delivering essential training to the large numbers can be costly. Added to this, some voluntary organisations report that they cannot access the free Highland Council training available to education and have to buy-in, which is also costly.

Many reported existing arrangements for training their staff to work with ASN within the contexts of their organisations, one organisation having a modular programme which included one on challenging behaviour. There is, however, an acknowledgement that lack of expertise in particular needs could be a barrier. One national organisation has resources for working with ASN on its website and also has a database of leaders with specific skills and experience who can provide advice. Some

commented that though their volunteers often had a high degree of commitment and expertise they often didn't have the time to train and that to impose this on them may result in losing their goodwill.

Integration of Services – there is a perceived lack of integration between adult and children's services with neither funding or provision being equitable. Some organisations with a holistic remit feel that funders are still locked into the old silos of care OR education and the organisations that span both are disadvantaged. There is some uncertainty as to whether the new integrated organisational structure introduced into Highland in April 2012 is improving this.

### Attitudinal Barriers

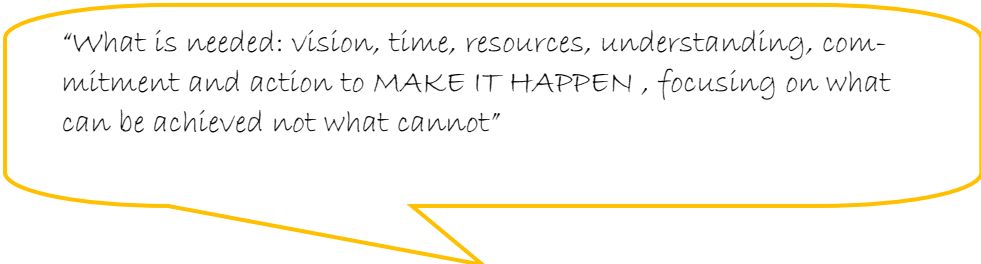


*"Some very successful and inclusive provision can be in very inaccessible accommodation with a challenging range of needs but it is the attitudes of the providers that are the key"*

Many providers felt that there was a greater awareness within society of many minority groups and of additional need generally, and that this has resulted in a better understanding both in schools and in society. Though selective and negative media reporting, focusing on certain groups within society, can have the opposite effect and results in the perpetuation of myths by prejudiced people. This is a huge barrier to the inclusion of their C&YP. Despite the improving picture and more tolerance of C&YP generally, societal attitude is still thought by many providers to be a big barrier to inclusion.

Social work services elicited comment from many providers. There is agreement that there are individual social workers whose professionalism is exemplary but the system thwarts YP at a time when they are very vulnerable. Providers report that there is no dedicated ASN provision within adult social work and on moving from children's social care all aspects of care are reviewed; consequently YP and families often find themselves without support and respite all at a time when they are suddenly bereft of the structure, routine and support of school and care. As the YP do not have the resources to cope without the support their destination beyond school often breaks down.

Though the situation has improved since GIRFEC (Getting It Right For Every Child) was introduced some providers feel that there are particular issues of information not being communicated effectively to and within schools, consequently individual



*"What is needed: vision, time, resources, understanding, commitment and action to MAKE IT HAPPEN, focusing on what can be achieved not what cannot"*

staff are often not aware of the context of the child's life within which difficult behaviour can occur. This lack of information about a C&YP's circumstances can result in the teacher apparently treating him/her inappropriately and without empathy and understanding.

## Conclusion

There are still some problems with barriers to inclusion; with venues - location and transport being the major environmental barriers with suitability, adaptability, availability all being mentioned.

Of the structural barriers perhaps training emerged as the major issue with availability of affordable training, the difficulties of having sufficient expertise within a staff team and of ensuring that volunteers access training to meet the needs of the C&YP they encounter, all cited.

Communication and attitude of services and professionals as they deal with each other and with the C&YP and their families are still issues and there seems to be a lack of confidence that measures to better integrate service provision are working.



## **Discussion : Inclusion –is it an improving picture?**

The 2005 HCF inclusion report “What Difference Would There Be If Children’s Experience Framed Policy” looked particularly at the integration of C&YP with ASN in schools. This report “Being A Part Not Apart” looks also at the general C&YP population. This must be borne in mind when comparing the picture of inclusion in 2005 with 2013.

It was clear during this consultation that there is a huge commitment to, and enthusiasm for the ethos of inclusion. Schools felt, as in 2005, that resourcing was crucial to successful inclusion and must be maintained, with staffing levels, transport funding and the school environment being mentioned. The impact of the needs of C&YP with ASN on the other children is an issue that was mentioned as in 2005.

There are anxieties that the current budgetary constraints e.g. cuts in admin. hours and increases in head teachers’ contact time would reduce the capacity of schools to maintain the structures that they have in place to support a positive and inclusive ethos.

Parents’ issues are very similar to those of 2005 with the parents’ main concern being that their child’s needs were met. There are still parents who feel that schools and services were too slow to acknowledge their child’s needs, that they were not listened to or respected as partners in decisions, and had unsatisfactory experiences of meetings.

Additionally, the 2013 parents of C&YP on the autistic spectrum are a significant group who feel that a mainstream setting cannot meet their child’s needs no matter what measures are put in place. It is clear that, as with HCF’s previous reports (How’s Your Journey? 2012 and Recipe for Young Parenthood 2012), the quality of experience is attributable to the attitudes of individual professionals encountered.

C&YP in school groups want to feel included, they want to be able to pursue their interests with their friends. Most of the children consulted felt included, some had no experience of ever having felt excluded. Inclusion for most of them, as in 2005, is in the context of friends and family with school being the most important context. Individuals with ASN consulted, want to be involved in decisions about their future, to be treated with respect and understanding and want an education which takes account of their needs.

Providers were not consulted in the 2005 study.

The picture, though it does not show significant improvements in the experience of inclusion over the last 8 years, does not show deterioration either, though there seems to be some crystallisation of views e.g. the parents’ view that mainstream is not always the right place for C&YP with ASD. There would be serious implications for the support of inclusion and ultimately for C&YPs experience of it should the budgetary situation become more challenging.

## **Recommendations**

### **Attitudinal Barriers**

Training issues should be examined—to ensure that there is not only sufficient basic training available but also more specialised training in specific conditions and behaviour management. The availability of affordable training to small organisations should be ensured. Ways to support the up skilling of volunteers, whilst acknowledging their considerable value and time issues should be explored. A database of people with specialist skills and expertise who could be approached for advice/ support could be maintained. Training programmes should be reviewed to ensure that they give sufficient time and depth to issues of reflective practice, GIRFEC, disability awareness.

Disability awareness within school PSE lessons as part of the Health and Wellbeing curriculum would help to break the cycle of societal prejudice and may reduce bullying. (HCF facilitated 4 YP with disability to produce a resource pack, consisting of a video, podcast and 7 activities referenced to the Curriculum for Excellence, which is available on GLOW).

### **Environmental Barriers**

C&YP with ASD emerged as a significant group for whom inclusion is not always best served by integration within mainstream. The C&YPs response and the parent's view should be valued more and planning for these C&YP should be more individual and more timely in order to reduce the numbers of them either out of education or attending part-time.

There should be more consultation with the 'experts' in disability access - the C&YP and parents themselves - to ensure that the design of public spaces and buildings (ref: parks and public toilets page 41) is fit for purpose.

### **Structural Barriers**

There should be more awareness of how certain classroom organisational routines can stigmatise children e.g. sitting all the children with ASN together, allowing team selection procedures to show diminishing popularity of children, the buddy bus-stop (Cited by some C&YP as a barrier but paradoxically by the schools as contributing to inclusion).

The ASC and YDO roles were so fundamental to the inclusion of C&YP in all 3 areas, along with the transport subsidies in the sparse area, that there would be serious negative implications for their inclusion should any of these be reduced.

## What Research says about Inclusion

Tam Baillie, Scotland's Commissioner for C&YP in his 2010 consultation to help define his priorities found that

*Help everyone to include each other, no matter how different we all are*

emerged as one of the top priorities. It has subsequently become one of the strands in his 2012-2016 strategic plan.

Stalker and Moscardini state that

*despite considerable efforts at all levels we know that many disabled C&YP do not enjoy the same chances as their peers....inclusion remains an aspiration.*  
Stalker and Moscardini "Critical Review and Analysis of Research and Policy Relating to Disabled Children" [www.sccyp.org.uk](http://www.sccyp.org.uk)

## What is Inclusion?

Inclusion is very difficult to define, having different meanings in different contexts. In the educational context it is often understood as the inclusion of C&YP with additional needs in mainstream provision but takes on different meanings in the wider context of social inclusion and in feeling to be a fully functioning member of society in general. Attempts to define inclusion seem to pose more questions than answers and reflection on its meaning raises a range of issues depending on context.

*It is a 'feel-good' expression that no one can oppose and yet no one can accurately define. Who is thought to be in need of inclusion and why?*  
Armstrong, Armstrong and Spandagou 2011 'Inclusion: by choice or by chance?' International Journal of Inclusive Education Vol 15. Issue 1.

Of the many different definitions of inclusion the Council for Disabled Children (CDC)(2008) puts it this way:

*Inclusion is a journey with a clear direction and purpose: equality of opportunity for all children and young people. CDC believes that the following factors are crucial to the development of inclusion:*

- a welcome for all disabled children, secure relationships and support for families when they need it;*
- respect for difference and a commitment to building friendships and community to the benefit of everyone;*
- equality of access to play, learning, leisure and all aspects of life;*
- active participation of children and families in decision-making;*
- a proactive approach to identifying and removing barriers;*
- timely access to information and to people with empowering attitudes, supportive skills and expertise*

Inclusion and integration are not synonymous. Inclusion means that the child and his/her needs are accommodated within the organisation (the social model), and the barriers to full participation are identified; whereas integration implies that it is the child that has to adapt to the organisation and to its peers (the medical model). Inclusion is a more values-orientated term and is based on the premise that all C&YP have the right to be included in settings and activities with their peers, siblings and friends. It requires a commitment by the whole community of the organisation to value C&YP for who they are, acknowledging the full diversity of the whole neighbourhood.

*Adults- whether parents, carers or professionals- need to provide a context for inclusion and be flexible in its interpretation. At the end of the day inclusion should defy definition except to say that it is infinite*

**Social Inclusion: The Way forward CIS Magazine June 2002**

## Educational Inclusion

*If education should be inclusive then what practices is it contesting, what common values is it advocating and by what criteria should it be judged?*

**Armstrong, Armstrong and Spandagou 2011 'Inclusion: by choice or by chance?' International Journal of Inclusive Education Vol 15. Issue 1.**

A narrow definition of inclusion in education concentrates on how a particular group can be accommodated whereas a broad definition looks at the diversity within the entire school community.

As the concept of inclusion has become embedded the understanding has broadened:-

*Educational inclusion is more than a concern about any one group of pupils such as those pupils who have been or are likely to be excluded from school. Its scope is broad. It is about equal opportunities for all pupils, whatever their age, gender, ethnicity, attainment and background.*

**Ofsted 2000 Guidance for Evaluating Educational Inclusion**

*Over time, the working definition of "inclusion" has changed significantly. It began with the desire to integrate children and young people who had additional support needs within mainstream schools and classrooms. It moved on to looking more closely at how best to meet the different needs of children and young people for example, those with noticeably lower levels of attainment, widening to look at children and young people with many kinds of barriers to making progress, and finally to success for all.*

**HMIe 2010 Count Us In: Success for All**



This paper argues that interactions of individuals are complex and so are the many factors that contribute to the richness of their educational experience.

Attempts to find simple solutions to educational complexity often lead to over-simplification and fragmentation – knowledge and skills are treated as though they can be learned without reference to the learners life beyond the lesson or subject.

It reasons that all who are involved with C&YP need to take account of

the whole set of attitudes, emotions, knowledge, developing abilities, need for and enjoyment of other people, ambitions and aims which make up their personality.

Creating and maintaining a school and community ethos where this can happen is in itself very complex.

Collaboration across research, policy and practice communities is not optional – it is the key...to real change, real improvement....There has to be real understanding and commitment to them by all, supported by research and policy. There has to be real community of belief.

Caroline Dunbar 2007 'With a Little Help from your Friends' CIS Magazine April 2007 is of the view that support from peers and C&YP feeling included are the keys to schools being more accessible. Adaptations to the environment and extra resourcing all help but what pupils really rate is friendship and feeling included. She also states that

The value attached to feeling included is far higher among pupils than is reflected in current policy and legislation, which focuses on physical and information barriers and access to the school curriculum.

Talking with YP and with parents during the course of this research has revealed many instances of 'informal exclusion'.

*The exclusion rate per 1000 pupils for pupils who have an additional support need is 4 times higher than those who have no additional support need. Pupil Inclusion Network Scotland 2012 Inclusion in Scotland's Schools: one year on, where are we now? (A report on Included, Engaged and Involved Part 2: a positive approach to managing school exclusion. SG guidance)*

The guidance clarifies that there is no such thing as 'informal exclusion'. Where a pupil is sent home to 'cool down' or for 'assessment related to behaviour incidents' s/he must be formally excluded and re-engagement on a part-time basis is a continuation of that exclusion on a part-time basis. Exclusion results in not only exclusion from classes but from other aspects of school that might be beneficial and /or protective – breakfast clubs, school lunch, after school clubs or sports clubs, social interaction.

## **Social Inclusion**

As has been suggested the meaning of inclusion is strongly related to context. Education is seen as a key driver for achieving social integration and cohesion and inclusive education should be seen in the context of social diversity. Attempts to separate the educational and social contexts of inclusion over-simplify the issue.

What's the Problem? CIS Magazine Sept 2002 believes that a common experience is that of physical exclusion, of not being able to do social activities with friends – catch a bus, get round the shops, sit with mates at the cinema/in cafés, use public toilets. This leads to a different experience of growing up compared to non-disabled YP with more dependency on family and adult relationships. This type of exclusion has a knock-on effect on relationships with peers and particularly non-disabled YP and is particularly obvious in leisure time – a time that is usually spent with friends.

This view is echoed in Point of Participation CIS Magazine Dec 2006 which states that barriers to negotiating social networks and friendships leave C&YP vulnerable to marginalisation and social exclusion. Policy has tended to focus on educational achievement as the key to improving futures, seeing C&YP as future investments. However social experiences are equally important to their healthy holistic development and this in turn impacts on their educational achievement and policy should better reflect the importance of social opportunity. C&YP need to be considered assets to their community rather than problems with real opportunities to shape their community e.g. Young Leader qualifications, Saltire Awards.

However, whilst there are many positive examples of participation it must be remembered that the existence of the opportunity for participation is not a guarantee that it is happening. C&YP who are involved in decision- making may be drawn from older age-groups or are high- achievers and may not fully represent the range of YP from the social construct to which they belong.

*Just because they are involved in decision-making does not necessarily mean that they will challenge exclusion or foster inclusion* Point of Participation CIS Magazine Dec 2006

Though the 'social model' of inclusion for all should remain the aspiration, as we make the journey towards this we must be mindful of the necessity that

*social inclusion should ensure that all C&YP have access to the facilities and educational pathways which best meet their needs...if this is what is required to meet a child's needs then it is as inclusive an action as enrolling his peer in the local mainstream school. Locational integration should not be confused with inclusion.* Social Inclusion: The Way Forward CIS Magazine June 2002

Whilst it is the case that the inclusion of many C&YP cannot be achieved without major improvements in resourcing and staffing levels perhaps the single most important factor in successful inclusion is the commitment, expertise and attitudes of service professionals that the child and his/her family encounter. Whilst delivering services can be seen as a profession there is the extra dimension of attitude – interested, friendly, caring, respectful- that is what is wanted and what much of the testimony HCF receives shows is, sadly, often lacking. Putting in place policies and protocols which give YP rights and choice does not guarantee friendly, caring consideration.

*We need to encourage all those involved with C&YP to take account of the whole set of attitudes, emotions, knowledge, developing abilities, need for enjoyment of other people, ambitions and aims which make up their personality, their individuality as persons... Research has shown that ideas have to be worked to deeper understanding by communities working collaboratively. Collaboration across research, policy and practice communities is not optional – it is the key to the success of any innovation that leads to real change, real improvement...Policies, intentions and staff development programmes do not achieve desired ends on their own. There has to be real understanding and commitment to them by all, supported by research and policy. There has to be community of belief.*

**Scottish Executive LTS 2006 Focusing on Inclusion and the Education (Additional Support for Learning) (Scotland) Act 2004: A Paper for Reflection**

## Appendix 1

### Generic Needs Questionnaire

**Some children (for any of the reasons below) have additional needs and may need extra services. Please tick all the boxes below that apply to any of the group.**

***This form will be kept confidentially; it will not be shown to anyone else.***

The child does not live with his/her family [*He/she lives with a foster family or in a residential home*]

The child's family does not have a home of their own to live in [*They live in temporary accommodation*]

The child's family come from a country outside of Britain [*English is not their first language*]

The child comes from a Gypsy or Traveller family

The child has someone in the family who needs their help to manage

Someone in the family has a problem with drink or drugs [*Even if this person does not live at home, the child will find school and friendships harder because of it*]

Someone the child loved in their family has died or left home

The child has been in trouble with the police [*Enough trouble that the police have had to come to their home and speak to the parents*]

The child has difficulty seeing or hearing [*Not just wearing glasses, but if e.g. they need worksheets in a different font size; or if he/she wears a hearing aid or has to sit near to the sound source to hear properly*]

The child has a long term condition or illness [*The child needs regular medical appointments for a long term condition e.g asthma, diabetes, cystic fibrosis*]

**The child finds it harder than other children** [*not just sometimes but most of the time*]

To move about or do exercise [*either gross or fine motor activity*]

To learn things

To talk and listen to other people

To control his/her actions and behaviour [*not just occasionally, but most of the time*]

## Appendix 2

### Key to needs used in charts on pages ?????

- A. The child does not live with his/her family [He/she lives with a foster family or in a residential home]
- B. The child's family does not have a home of their own to live in [They live in temporary accommodation]
- C. The child's family come from a country outside of Britain [English is not their first language]
- D. The child comes from a Gypsy or Traveller family
- E. The child has someone in the family who needs their help to manage
- F. Someone in the family has a problem with drink or drugs [Even if this person does not live at home, the child will find school and friendships harder because of it]
- G. Someone the child loved in their family has died or left home
- H. The child has been in trouble with the police [Enough trouble that the police have had to come to their home and speak to the parents]
- I. The child has difficulty seeing or hearing [Not just wearing glasses, but if e.g. they need worksheets in a different font size; or if he/she wears a hearing aid or has to sit near to the sound source to hear properly]
- J. The child has a long term condition or illness [The child needs regular medical appointments for a long term condition e.g asthma, diabetes, cystic fibrosis]

#### **The child finds it harder than other children** [not just sometimes but most of the time]

- K. To move about or do exercise [either gross or fine motor activity]
- L. To learn things
- M. To talk and listen to other people
- N. To control his/her actions and behaviour [not just occasionally, but most of the time]

# References

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# Relevant Legislation

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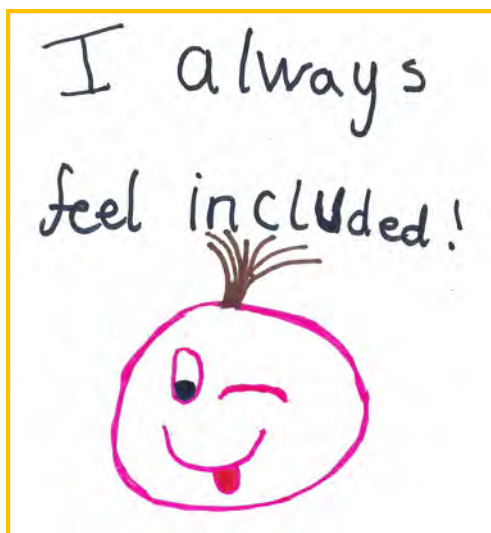
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