

Families for Change

Promoting and defending the rights and interests of people with a developmental disability.

Summer 2004

Volume 2

Issue 14

family
ADVOCACY

The road to an inclusive adulthood – investment needed now!

This edition of the newsletter highlights what needs to happen if students with disability are going to be well educated in the regular classes of local high schools and have their expectations of a good life realised when they leave school. Without investment by Government in an effective road-building program, too many students will end up in side roads, which will lead them away from their preferred destination.

While there is still a lot of work to be done at the primary school level, it is to high school that parents and students are now looking for a welcoming attitude and the adaptations needed to ensure inclusion.

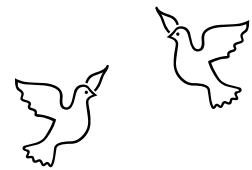
In recent times, Family Advocacy ran a “phone-in” over several days and heard from parents about the opportunities and barriers at the high school level. This has provided a snapshot of what needs to happen as more and more students with disability move from the regular class in primary, to the regular class in high school. There appear to be many more barriers than opportunities at this point in time, but we are confident that this will change.

A lot of work has been done in some schools and through the Access and Participation Unit of the NSW Department of Education & Training, to ensure that students are well supported in high school. Julie Hook played a significant role in these developments, and her contribution highlights some practical strategies schools can enlist when enrolling and educating a student with disability and significant support needs. The article points

to some of the ways, which have enabled high school inclusion for many students around the State.

Last July, the whole future of post-school opportunities for young people with disability was put in doubt when the Minister for Disability Services announced very significant and, in our view, largely negative changes to the policy and funding which underpin the current post-school environment for school leavers. While a campaign is still continuing, Zoe Satherley’s account of her son Joel’s experience is a great story. It demonstrates the power of positive thinking, individualised funding, creative ideas, staying power and strong values.

Also, in the midst of the campaign, we heard of a parent from Nova Scotia, who was on her way to speak at a conference in New Zealand on the experiences of a small, family-driven, community-based organisation (CAPRE) which assists young people with significant disability to create their own business opportunities upon leaving school. It was too good an opportunity to miss, given the current circumstances, so Family Advocacy brought her to Sydney, where she spoke to a large group of people with disability, parents, support workers and service providers. The story of their journey - their struggles and successes, which began while the young people were still at school, really brought home the importance of believing in people’s capacity for ongoing learning and development, maintaining high expectations, and avoiding the trap of thinking “some people are too disabled for work” – CAPRE has proven that where there’s a will there’s a way!



“The Management Committee and Staff of Family Advocacy wish you much happiness for the festive season, and peace and empowerment in 2005!”



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More Than A Visitor: Meaningful Inclusion Of Students With A Disability In Secondary Settings

As Team Leader of the NSW Department of Education's Access and Participation team since its inception, Julie Hook, explores with 'hands on' experience, the features of effective high school inclusion and the processes that need to be in place when planning for successful transition. Julie now works as a consultant, having left the Department of Education in September 2004.

Over the past few years, parents have increasingly made the choice to enrol their child with a disability in their local primary or secondary school. While there has been much written about the positive impact of inclusion on students with a disability and their peers without a disability – the road still sometimes remains a bumpy and difficult one for many families.

In its truest sense when we talk about inclusion or inclusive education we need to talk about a **process** of managing a school or class as a 'supportive community' which accepts and caters for student diversity. To support and facilitate this process several critical elements need to work together.

These elements are:

- **Positive school leadership**
- **Proactive planning and partnerships**
- **A culture and structure that encourages membership, belonging and active participation in the 'life of the school'**

These elements need to co-exist and interact within a **systemic framework** that provides support and direction. Within this systemic framework, we talk about things such as funding, staffing, professional learning for schools, the use of support personnel and a curriculum framework.

Leadership:

Schools are complex and dynamic communities and are increasingly challenged in meeting the learning and social needs of a diverse range of students. Strong positive school leadership that encourages and supports an acceptance of student diversity and importantly a willingness to overcome the 'fear factor' is an essential ingredient of

"Being a valued member of a class, school and community is what we all aspire to for ourselves and our children."

an inclusive school community. Schools may not always have all the answers - but having a school that is willing to 'give it a go' and be prepared to tread new and unknown territory will be 'music to the ears' of most parents of a child with a disability.

But strong, positive, supportive leadership, while an essential element, is not enough

Successful inclusion also needs **proactive planning and partnerships** between schools, families and other agencies.

Proactive planning and partnerships is about:

- identifying a small number of achievable, realistic and meaningful learning goals for the child/young person as part of a collaborative planning process...
- providing learning supports and adjustments that enable a student to access and participate in the life of the school and class...
- ensuring that these learning supports and adjustments can be sustained and that they encourage a sense of belonging and membership. Michael Giangreco, a well known researcher in this field, refers to the provision of supports that are "ONLY AS SPECIAL AS NECESSARY"...
- identifying what support the school needs, and importantly, the class teachers need, to develop their understanding, knowledge and skills...
- providing opportunities and a culture that allows for creative problem solving and flexible solutions...

- knowing where to go to get help e.g from other teachers in the school, from support personnel in the local area, families or other professionals...
- partnerships with other agencies such as local mental health agencies and local therapy teams.

There are 2 key questions that can guide this planning

Can this student access and participate in the life of the school, the class, and class activities, in the same way as other students?

If not
What learning supports/adjustments are required?

(Questions adapted from Jorgenson, 1998)

Some examples of learning supports/adjustments include:

- whole school considerations such as flexibility with the timetable, location of classes...
- playground support...
- specialist equipment such as modified desks, hearing loops...
- peer support...
- professional learning for staff...
- provision of teacher aide support for some activities to facilitate the students participation...
- access to technology.

Successful inclusion of students with a disability in regular classes is not about transposing a more traditional special education approach in a regular class

setting – it’s about identifying the learning supports and adjustments required to enable the student to be a valued member of the school and class.

Membership, belonging and participation - what does this mean?

But what does this mean and how does it look like for students with a disability enrolled in secondary schools? Some secondary aged students without a disability were asked to talk about what class membership and belonging meant to them, and they said:

- having a place in the classroom...
- feeling respected and wanted by the teacher and other students in the class...
- being talked to by the teacher...
- being talked to by other students...
- having questions asked of them by the teacher that they could answer...
- participating in class activities...
- having friends.

These students were also asked how they perceived class membership for students with a disability and they said that a student with a disability needed:

- an opportunity to participate in the same class activities as them even if it was in a different way...
 - opportunities to communicate and interact socially with others, even though the way that these students communicated was different.
- (Tennant, 2000)

For students with a disability to be meaningfully included in regular classes, they need to be valued by their peers. That is, a student with a disability needs to be provided with the opportunities to take part in the same activities as other members of the class even though they may do this in different ways.

This may mean that a student with a disability is:

- working on different outcomes within the same unit of work as other students...
- presenting their work in a different way e.g. using a PowerPoint presentation

- or by creating a visual representation...
- using a voice output device to enable them to be a leader in a group...
- working with peers in a small group...
- needing other students to learn how to communicate with them.

Meaningful inclusion of students with disabilities does not mean a separate educational program - it’s about a whole class program that caters for the diverse learning needs of all students.

The NSW Board of Studies has developed an inclusive curriculum framework that supports this philosophy. The new 7-10 syllabus framework includes learning outcomes and content designed to meet the needs of **all** learners in all syllabus areas. This means that students with a disability in secondary schools can access relevant outcomes and content, and be assessed against these outcomes in any subject area. These outcomes may be ‘regular’ outcomes or they may be ‘life skills’ outcomes, dependent upon the decisions that have been made for the student, as part of collaborative planning processes at the school.

If students with a disability enrolled in secondary schools are to be **‘more than a visitor’** then the language of **leadership,**

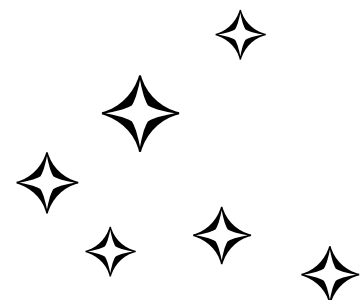
planning, partnerships, belonging and participation need to be used synonymously with the words inclusion and inclusive education.

References:

Giangreco, M.F., Broer, S.M & Edelman, S.W (1999) *The tip of the iceberg: determining whether paraprofessional support is needed for students with disabilities in general education settings.* Journal of the Association for Persons with Severe Handicaps, 24, 4, 281-291.

Jorgenson, C.M (1998) Restructuring High Schools for all Students: Taking Inclusion to the Next Level Paul H Brookes Publishing Co: Baltimore.

Tennant, L (2000) *Students with severe disabilities in inclusive education classrooms.* The Delta Kappa Gamma Bulletin, 66, 3, 17-23.



What’s new on Family Advocacy’s Website?

- “Education in NSW” – keeping you abreast of issues as they happen. Follow the link from our Systems Advocacy Page.
- “Atlas and Post School Options” - watch the “What’s New” section on the home page for regular updates.
- New links added to the side navigation bar for easier surfing.
- 2004 Family Advocacy Annual Report now available on-line.
- Register to receive our bi-monthly news bulletin ‘Communiqué’ or ‘Families for Change’ via email.

For further information or assistance in using our website please contact Karen Mackie ph: 02 9869 0866 or via email: karen@family-advocacy.com

Negotiating inclusion in high school: Parent advice to the Department of Education and Training

Belinda Epstein-Frisch, Family Advocacy.

For a long time Family Advocacy has known that there is a need for proactive strategies to prepare secondary schools for the increased enrolment of students with disability who expect to move with their primary school peers to the regular class of their local high school. Families have seen the many benefits for their children throughout their inclusive primary years and want to see it continue into High School. Unfortunately, the phone calls Family Advocacy receives from parents across NSW on a daily basis, demonstrate that appropriate preparation of high schools has not yet occurred.

The following article, which also includes information gathered during a recent 'phone-in', reports the experiences of families in the process of having their sons and daughters included in the regular class of the local high school. Learning from their experiences, parents offer advice to the Department of Education & Training (DET) as to ways in which the process could be improved including a welcoming attitude in schools, Principals that show leadership, having genuine partnerships with parents, decisions in the transition process made in a timely fashion and a prohibition against DET pressuring parents into support units.

Transition

Parents report frustration about the process of transition to high school when they are in fact, keen to establish collaborative relationships with school staff. They know that this is the basis of a partnership that they hope will support the school to provide an effective and supportive education for their child over the next 6 years. The experience, however, is that the choice of the regular class in high school is not supported by many school executives nor the School Education Area Office. Parents are given misinformation about support in high school and are regularly informed that their child will NOT receive funded support in the regular class. Parents consistently come face to face with the fact that IQ scores and labels create low expectations and significant barriers to inclusion. Their experience is that a low IQ or high support need increases the pressure for placement in a support unit.

Delays in decision making are a source of enormous angst, and despite parents providing 2 years advance notice of choice of their local high school, there continues to be insufficient lead time for capital works. The frustration continues once enrolment is offered, with schools slow to identify the teachers for year 7 or put in place processes to facilitate communication. The inevitable result is inadequate preparation of teachers and increased anxiety for families.

Some parents experience difficulties in transition from year to year. The

“ that (one of) the crucial factors affecting success are: a Principal or teacher who believes that the child had a right to be in their class. This moves discussion out of the realm of ‘why’ into the practical realm of ‘how’”.

knowledge and skills of year 7 teachers, gained through training and development and experience, are often not passed on to the teachers for year 8. A number of parents feel that their knowledge about their child is not valued in transition planning and certainly is not passed on to teachers.

Support for the individual student

Parents' experience of the support provided to their sons and daughters is variable. At one extreme, some parents report that a lack of understanding of their child's disability leads to a lack of preparedness by the school to seek funding support and make appropriate adjustments.

Many teachers refuse to adapt curricula, arguing that if the student wants 'something special, they should go to an SSP'. Families often report that their son or daughter is effectively 'disadvantaged' when all is going well, with a reduction in the support that had been so essential to their quality inclusion. Other families believe that the level of support does not take account of factors associated with the school, with the same level of support in year 6 as in year 7, cited as an example of the inability of the system to take

account of the new challenges as children progress through high school.

The barrier to inclusion most consistently reported by parents is the all-pervasive growth of support units. Parents of children who have been included all the way through primary school are pressured to place their child into a support class for high school. A phone call to the Principal of the local high school for a preliminary chat about enrolment is almost always directed to the head teacher of the support unit.

Families

Many families are critical of the so-called partnerships between themselves and the school believing that 'nothing would happen without their pushing'. A number of parents were particularly aggrieved when the expertise of a new graduate teacher was seen to surpass the knowledge of the family.

One of the most important processes to facilitate partnerships with parents is the Learning Support Team (LST). The team comprises parent, teacher, and anyone else with a role around supporting the student's learning. Some families had never heard of an LST, and others

report important decisions already being made prior to the meeting of the LST and they therefore question the school's commitment to the process and the concept of partnership.

School

The major role of the Principal in determining whether or not the culture of a school is inclusive and whether or not supportive structures underpin this culture is well accepted. Many parents report that their school Principal seems removed from the concerns related to an individual student. In the main, Principals are not seen as responsive to families, backing teachers in any area of disagreement.

A number of parents identify features of schools that impede successful inclusion. The lack of support received by, for example, a new graduate teacher to modify curriculum, was highlighted. This is all the more frustrating when competent, expert staff and consultants are

available to the school but work through withdrawal of the student for one-to-one work rather than providing guidance and support to regular class teachers. A number of parents report that school staff refused training and development or consultancy opportunities.

It is also frustrating to parents when their views are not taken into account in the employment of a Teachers Aide Special (TAS) for their child. For students with high support needs it is widely felt that an inappropriate TAS can inhibit opportunities for relationships and so the employment of the 'right' person is crucial for success.

It was pleasing to note that, one parent reported her school used part of the funding support for an Inclusion Coordinator, a member of staff who became the focal point for sharing information and anticipating and addressing systemic issues. This had improved her son's inclusion immeasurably, reducing stress

on the student, his teachers and the family. This shows how lateral thinking and preparedness on the part of the school to be innovative, can achieve a benefit for the entire school.

Overwhelmingly, families believe that the inclusion of their son or daughter in the regular class of high school is well worth the struggle. Their experiences of inclusion lead them to advise the Department that the crucial factors affecting success are:

- a Principal or teacher who believes that the child had a right to be in their class. This moves discussion out of the realm of 'why' into the practical realm of 'how'...
- genuine partnerships with parents...
- support for the regular class teacher by people who understand inclusion...
- use of funding support for arrangements that break down barriers to inclusion and facilitate the sharing of information.

Resources from the Inclusion Collection ...

Books:

Making Self-Employment Work for People with Disabilities

This handbook offers practical advice to help individuals with significant disabilities start and maintain a small business. (Cary Griffin and David Hammis, USA, 2003.) File No: 3288

Like a sweet cup of tea: shared lives, neighborhoods and communities

With the intention of encouraging a stronger movement in favour of authentic community living, and underpinned by a theme of reconciliation, this book provides stories of people with disabilities living ordinary lives, in valued roles, and in love relationships, and explores the ethics and practices that make this possible. (Community Resource Unit – QLD, Australia, 2004.) File No: 3289

Articles:

Building Inclusive Capacity at School: A Practical Conversation with Educators

This article extracts a conversation with the Deputy Principal and senior teacher of a Perth primary school which has implemented a unique model of inclusive education. The Principal acts as an advocate with students and their families during their transition to high school to ensure that this model of inclusion continues. (Kylie Smith and Val Evans – Australia, 2004.) File No: 11104

What do you want to be when you grow up?

A mother shares insights into the importance of life-long learning for children with developmental disability. Parents and teachers should encourage children with disability to dream and set goals, as high expectations lead to successful life-long inclusion. (Robin Acton – Canada, 1998.) File No: 11058

Order resources online or contact Karen Mackie on 02 9869 0866 or via email karen@family-advocacy.com

From School to TAFE but where to now?

Zoe Satherley has been associated with Family Advocacy in a number of different capacities for the past 10 years. She currently lives in Lismore, has two children - Tessa and Joel.

Zoe has brought significant change into Joel's life.



Joel Satherley

For Joel, life is about dreaming of the next roller coaster ride. That is his obsession. For me, every day seems to be a roller coaster ride. I get gut-wrenching reactions and feel pale and light-headed, but it's not from the thrill of loops and spins. It's more from facing the demons of fear and uncertainty about his future and struggling, week-by-week, to build a good life for him in the community.

Joel is turning 21 soon. His future is an open book. How it gets written will be largely up to the planning and visioning I do with the help of those who also love and care for him.

Last year was his first year out of high school, having completed Year 12 following a Life Skills curriculum in a regular class at Nimbin Central School. It was a huge year for him. So much changed. His Dad and I became estranged and moved into separate houses. His beloved sister moved to university in Melbourne. His best school friends moved away for work and study and I got a demanding full-time job back in my first profession, journalism, that keeps me away from home for long hours.

Joel received ATLAS funding and some support through the now largely defunct Service Access System (SAS). Without

that crisis funding, our lives would have collapsed. During the year, Joel had to learn to cope with 12 different support workers. He went to TAFE to study theatre practice. I made a presentation in front of a selection panel to present the case for his selection in what was a popular course with more applicants than places.

The drama he had done in high school was well regarded and I was glad we had filmed so much of it, as we were able to put together a compilation tape, as Joel did not have the language skills or emotional capacity to be able to attend an interview and speak for himself. Joel's inclusion in the class proved a challenge for his teachers and almost every subject and every assessment task had to be modified in some way. Dance was interesting. It often took two people to hold Joel up and help him move. Many moves had to be modified or done from the floor. This sometimes led to interesting challenges for the other students when they were asked to join him as he led the improvisation.

When he had to do a 'stand-up' comedy routine in a Byron Bay nightclub with other class members, he brought the house down by appearing on stage and complaining "I can't do stand-up without falling over!". A person was prompting him from the foot of the stage but the place was so crowded, no-one noticed. Even though people could only catch bits and pieces of what he said, it didn't matter. Everyone was just so delighted to see him up there having a go. He got the biggest applause of the night and felt justifiably proud of himself.

The technical subjects, like lighting and sound, have presented the biggest challenge. However, he has been there. a part of the class, even if at times he only contributed a simple instruction to 'turn on the switch'. Written assignments have

had to be modified with Joel allowed to answer questions verbally. I have to say his team of TAFE teachers have been outstanding. They took ownership of Joel and his learning from day one and at all times have treated him with a great deal of respect and dignity, as they have with all the students. I wish all teachers were that positive and that welcoming.

The drama course has now drawn to an end and we have to look at what Joel's next focus will be – drama with a local theatre group, learning how to play drums, two-fingered electronic keyboard improvisation, art classes there are many options but the key is finding the ones that Joel finds engaging and is keen to pursue.

His foray into the world of university early last year, when he did one subject in a creative writing course, was an interesting exercise. I jumped through so many hoops to get him a place - you've got no idea the work that went in to making it happen - but then he decided he didn't like it much! Aaagh!! Still, if you don't try these things you'll never know.

One infuriating experience I had at the beginning of this year, when Joel was having trouble settling back into TAFE, was being told by both his Dad and his main support worker that they felt I was pushing Joel to attend classes against his will and causing him undue stress. Today they both look back at Joel's tremendous achievements and how much he has enjoyed his course and are glad I pushed them through the rough patch. Success is so fragile. Not everyone shares your vision or believes it is possible.

My next main idea is to get Joel a theatrical agent and see if we can get him some bit parts in a TV show like Home and Away, for example. I think the world is ready for people who have multiple disabilities to be on our TV screens in valued roles, don't you?



Canning Area Parents for Real Employment

On December 1st, 2004, Judy Van Amerongen participated in an 'Innovative Employment' workshop hosted by Family Advocacy. Judy shared both her experiences and her vision for supporting people with significant developmental disability into meaningful employment. This article reflects on the development of CAPRE - a case study of what can be achieved when you have a dream for a better future.

As our children were growing and maturing, we wondered what kind of future they would have. At the time, most of us belonged to a group called "The Parent to Parent Support Group". One of the first things we did as a group was toured the existing facilities in our country. There were long waiting lists and it was apparent there was nothing out there for our children with significant needs.

In 1986 we began meeting to explore future vocational options. It seemed natural to shift priorities to more appropriate work related activities. Like any parent, we wanted our children not only to be happy, but to be contributing members of the community, living with dignity and respect. We wanted people to see our children through our eyes and see that they had something to offer.

Around this time, the concept of supportive work emerged from Virginia in the US. This was a new concept and receiving some recognition. As we had expressed an interest in employment options, a team was sent to our community. We had three days of meetings and discussions. In the end, the verdict was that supportive employment was not an unrealistic goal for our children.

In 1987 we ran our first supportive summer work program with 3 individuals (still in high school), selected to work in the community. During that first year we received 33 no's from employers, but by mid summer had jobs for all 3, two of which were paid positions! As a group we adopted the name: Canning Area Parents for Real Employment or CAPRE as it is known today.

Our objectives have become:

- To create meaningful community based self-employment or equal employment for all citizens of the Canning area, regardless of ability, by focusing specifically on the needs of those with intellectual disability.

- To increase community awareness of the benefits of self-employment or equal employment for all citizens regardless of ability.
- To become a support network to assist other parents or parent groups interested in supportive self-employment.
- To provide an environment that enhances the ability of all participants to communicate and to reach their full potential.

For 13 summers, CAPRE organised a supportive summer work program that included fun activities as well. We went from supporting 3 individuals to 12. Jobs were everything from small tasks such as filling a pop cooler, watering plants on the main street, to farm labour, child-care and wait staff in restaurants. Partnerships with local business developed those first years. The Rotary Club assisted with some costs and local high schools allowed our staff to come into schools prior to the summer break to allow us to work out the best placements and the support needed for individuals leaving school and coming into the program.

As our children became young adults we began to face the challenge of permanent long-term employment. We looked at our first young person to need full-time work, Krista, and began to think creatively about what her options may well be. We looked at her skills and her personality and came up with a business idea that seemed to suit her brilliantly. She is a bright, bubbly, busy girl who loves people and with an initial small grant from Community Services, she began a small errand service. I am happy to say that she is now in her 10th year of operation.

Probably the smartest thing we ever did, was to partner with other service providers who were able to help us with things such as small grant applications, staff training, access to equipment, and funding for transportation. We were vigilant about including everyone on our list of partners when we sent out end of term reports.

"Like any parent, we wanted our children not only to be happy, but to be contributing members of the community, living with dignity and respect."

We then pulled together a group consisting of parents and our partners to consolidate our efforts and to ensure that the business of supporting our children into employment would be enduring. CAPRE was born after 2 years of meetings and discussion and drew its seed funding from the Department of Community Services. It operates under a board of directors, which is made up of a combination of parents, advocates and community representatives. We now have 2 full-time support staff and 3 part-time staff, plus a Director. Each participant in the program has a support circle, consisting of the participant, a parent or advocate and business mentor, who will assist them to carry out their work duties. The responsibility of the support circle is to develop and nurture the business. The responsibility of CAPRE is to develop and nurture the young person, or as they are called at CAPRE, the entrepreneur.

The long-term aim for each business is to become self-sustaining, financially viable and largely independent of CAPRE.

Over the years we have learned much about our sons and daughters - they in turn have learned to be good workers. they are recognised as part of the community. People have had the opportunity to get to know them and realise that they do have something to offer.

For more information about CAPRE you can visit their website <http://www.nsnet.org/capre/> or follow the link from the Family Advocacy website.



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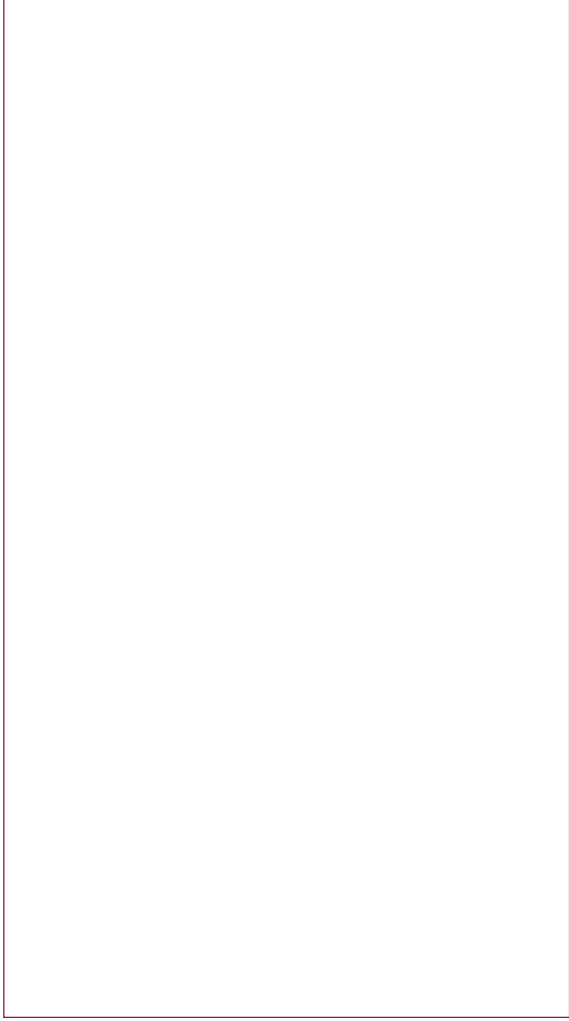
Family
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