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## “The Challenges Will Remain”: Systemic Work with Families of Children Needing Extra Care

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### Introduction

After working as a systemic therapists in many different contexts over the several decades, it is our observation that systemic family therapy is often associated with an understanding and expectation that problems and challenges in families and family living can and should be solved and forced to disappear with the help of various kinds of systemic interventions. Most models of family therapy and systemic work include an understanding of how problems develop within systems and how therapists can help the system to act in ways that make them disappear. Across the same time period, the systemic field has broadened in its conception of itself, and this broadening is nowhere more evident than through the introduction of the term ‘systemic work’. Systemic work

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is the term now used to depict professional practice in many different kinds of working contexts such as child protection services, kindergartens and schools (see Chapter 7 by Axberg and Pettitt, this volume, and Chapter 10 by van Roosmalen, this volume). This chapter will concentrate on systemic work with families with children that have different and various kinds of difficulties that they have had since birth or as a result of accidents and injuries. The children in the families we are focusing on here have one thing in common, namely they all suffer from chronic or long-lasting conditions. An incomplete list of such conditions includes severe Diabetes, Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Tourette's Syndrome, Down's syndrome, Developmental Disability, physical injuries or other conditions seen as incurable. A further common factor is that the families are in contact with many different services within the helping system such as specialists within hospitals, social welfare services of different kinds and institutions that provide "relief" and practical help and support. The task for services involved can be a combination of assessment and treatment with respect to the different conditions connected to a specific syndrome, sickness or injury and the provision of different kinds of support. What has been missing historically for these families in the Norwegian context, is a service that provides parental and family guidance and support to cope with a situation that is and probably will be affected by the conditions mentioned above and their consequences for the foreseeable future. The common factor for most of these families is that they have daily challenges that must be solved daily and that such challenges will not disappear or go away. The challenges will change, but they will almost always remain in one way or another.

Families in such situations often experience that the different parts of the helping systems they are in contact with cooperate poorly and that they, as parents, must be the bridge between them. This "job" often takes a lot of time and resources from parents who are already in a situation that demands great effort from them in taking care of the daily needs of the child who needs extra care and the needs of that child's siblings. The individual agencies that together make up the overall helping system mostly offer help of high quality but users often experience them as poorly coordinated and fragmented (Rogne, 2016).

Overburdened parents find that they must compensate for the deficits in coordination between services by functioning additionally as a kind of infrastructure of information between services. An example of this kind of additional demand arises from the fact that helping and school systems are often organized by age—categories which means that families must live with the fact that they often have to say goodbye to helpers and teachers when their child reaches a certain age and to establish new relations with a new set of helpers.

In presenting this chapter within a volume on 'new horizons' within systemic therapy and practice, we wish to emphasize two matters. The first concerns the newly evolving recognition of this arena of systemic practice as a specialism in its own right. No longer regarded as a field of practice where the novice practitioner may dip in and out to learn and practice discrete systemic skills with a client group who will 'always be there', work with families where children suffer with chronic conditions must now be viewed as a practice domain that demands a very broad range of systemic skills made available in the service of the whole family and its constituent parts in addition to the performance of these skills as part of a co-ordinating function aimed at enhancing the connectedness of the family's helping system as a whole, thus unburdening parents and children from a responsibility they should not, but often do, have to bear. The second matter is a consequence of the first. Because the work involves a type of systemic practice operating on many different levels simultaneously, it offers the experienced practitioner entry to a highly complex social field wherein new and unexpected opportunities for professional and personal development abound.

Our purpose in this chapter is to describe a variety of systemic practices with families with children that need extra care and where these family and child challenges will probably remain in some way or another. How can we characterize good systemic interventions in such family contexts? What do these interventions look like? We will also try to describe the systemic interventions that are responsive to the challenges arising from the poorly coordinated systems of help that surround these families.

The experiences this chapter is built on have their origin in a service established and developed in a middle-sized Norwegian city where the

main task of the service is to support the families described. The service is called “the family – guidance service.” The first author has worked in this service in the past and remains connected to it. The remainder of the chapter will be organized in the following way: following a description of the family-guidance service three family vignettes will be described in addition to the systemic work that was performed with each of the three families. This will allow the reader to receive a rich description of a small sample of systemic practices/interventions that respond to a highly differentiated arena of families with children that need additional care of one kind or another. The reader will also be invited to note the many different, and often competing, theoretical frameworks that underpin the rich variety of practices that comprise this area of systemic work. The vignettes will be followed by a reflection upon the shape of the therapeutic relationship in this area of work with additional attention being paid to the support required for this key relationship at the heart of the practice.

## **The Family-guidance Service**

The family-guidance service (FGS) began in 2018 and the main purpose of the service was to support families with children with special needs with guidance and supervision as an addition to practical help. According to Norwegian law, local municipal authorities are obliged to give parents with children that have special needs guidance in how to cope with their situation. The content of the guidance is not defined in the law, but traditionally such service has been seen as experts giving practical advice about “how to do it” by educating care—givers on how to cope with different kind of challenges such as aggression, sleeping problems, school—refusal and so on. The FGS was initially designed to do something else but their function was not clearly defined or described.

How to organize a new service, and where to place it within a larger organisational framework is always an important issue that needs thorough consideration. In this municipality, the provision of health and social services is organized in a way that people that need help

apply for this to a central unit. Case-managers assess the application and decide what the individual or family will be offered. In this process, the case-manager usually collects information by interviewing the person or persons that have applied, considers their requests against the background of usual service responses and subsequently discusses with colleagues and leaders what might be reasonable to offer. The assessment could then be discussed with the applying person(s) but not always. The process and the decision is based on the “Law of health and social services” and is always communicated in written form. The decision is sent to the person and to the municipal service that would carry out the delivery of the service response. What was experienced in the earlier phases of the FGS was that there was often a kind of “gap” between what the case-managers and their leaders considered as good enough help and what the receiving persons’ experience was of the help offered. The FGS was organizationally located among the case-managers who assigned work directly to the FGS staff.

When this service was started it was a key-point of its foundation that families’ descriptions and stories about what they felt they needed should be one of the pillars or cornerstones in the working relation between the family and the therapist. It was also decided that the service should be based on a systemic understanding that implies seeing human behaviour and all phenomena in context (Bateson, 1972). This also implies a relational view of life which means that what’s happening between people is the therapist’s central focus. But now, I will turn to the three vignettes. Each vignette depicts a child and parents facing unique challenges associated with a particular chronic condition and tells the story of how the FGS tried to help them and their response to this help.

## **Advocacy as a Systemic Intervention: Gabriel and His Mother Claire**

Gabriel is a boy of 11 living with his mother and with no contact with his father in the last 5 years. He has two grown up sisters living in another part of the country. Gabriel’s mother has not been able to work for the last two years due to health problems including a condition of severe

fatigue. She has now very a small income support from the social welfare office through decisions made for 6 months at a time. Gabriel is diagnosed with Autism Spectrum Disorder (ASD). He started school when he was 6 years old, but after 6 months it was almost impossible for him to be at school more than one or two days a week and then maybe only up to an hour at a time. This has been the situation since. He is now attending the unit within his class designed for pupils with ASD struggling with coming to and staying at school. One of the goals for him at school is that he should be at school for about three hours every school-day, but quite often he does not manage to come to school more than once a week and for some weeks not at all. His mother use to drive him and follow him into the classroom. Many efforts had been made to try to improve the situation. The role of the “family guidance service” was to offer Gabriel’s mother Claire guidance sessions and one of the purposes of this offer was to help Claire to help Gabriel to come to school more often. Claire said yes to this offer although she also said she did not have very high expectations regarding the usefulness of this. She also told the therapists after a while that she had felt that there was no option to say no.

In the first session, we talked about Gabriel and her history, and she told us that she was exhausted after years of worries and uncertainty. Duncan (2014) proposes that agreement between therapist and client about goals is important in order to succeed and be helpful. Based on that we started to make a list of what worried her in order to sort out what topics she perhaps wanted to focus. It soon became clear that what worried her most was her economic situation. She had not been able to work for many years due to her physical condition and the family situation and she no longer had a right to be reported sick from her doctor which meant that she had to rely for her income on social welfare who made decisions about financial support for three months ahead. The amount of aid was limited, and Claire had to be very careful about what she used money on. She also said that she, through the clinic that had assessed and treated Gabriel, had participated in courses and other kind of psychoeducational activities and she thought that she had a good grip on what ASD is or could be and how this affected Gabriel and herself. She knew when she could push him a bit more in order to help him go

to school or participate in social events in the family, such as birthdays, Christmas and so on and when she could not. She did not feel the need for more education and advice on how to cope with the situation and she also felt that the helping systems questioned her competence and that this was an additional burden.

We then talked about how she thought or wished the family-guidance service could assist her. She said that she really did not know and that she had said yes to come to talk with us mostly because she felt that she had to say yes. We talked about how we (FGS) could be a resource for her and Gabriel and not an additional work task that could turn into an extra burden. Would it be of any help if we also met Gabriel? Should we have the sessions at their home with them both? Did she want us to experience alongside her how she and Gabriel interacted in challenging situations? Claire said no to these suggestions, and after a while she said that she felt what was most stressful to her was her income situation, which she assumed we could not help her with. Minuchin (1991) criticized post-modern and social constructionist-oriented family therapy for seducing people to believe that problems could be dissolved (and solved) in language by developing a different way of talking about what is challenging. Sundet (2009) points out the importance of the therapist's willingness to support their clients also in practical ways, such as using their authority to impact the client's essential life conditions. As a therapist in this situation, I thought it would be of limited help for the family to talk to me about how stressful it is to not know how much money they had at their disposal the following month. This would hardly help and certainly would not solve the problem or create a more predictable income situation. This challenge is a part of the context (Bateson, 1972), and a systemic therapist should always be aware of the conditions under which their clients live and be ready to help them with these in so far as they can.

In this situation, I asked Claire for permission to talk to her case-manager in the social welfare department about her situation and to spell out how her circumstances affected her ability to be a mother to a son that really needed much input from his surroundings. She said yes to this and I made contact with the case-manager and pointed out that working on parental skills which requires a lot of psychological effort is

a very different task when you are stressed about your basic life conditions. The case-manger understood this and made a formal decision on financial support within a longer time horizon. For Claire, this meant less concern and stress and a better capacity to withstand demanding situations together with Gabriel.

Gabriel showed a lot of anxiety in transitional situations in general (leaving home for school) and in social situations including with persons he doesn't know. These feelings could often overwhelm him and force him to stay at home instead of going to school. Anxiety and other affective disorders have been reported as co-morbid conditions to ASD (Hudson et al., 2017; van Steensel et al., 2013). In addition, a higher level of attachment difficulties are also reported in children with ASD in contrast with comparable groups (Naber et al., 2007; van Ijzendoorn et al., 2007). These feelings could often overwhelm him and force him to stay at home instead of going to school. In such situation, he really needs his caregivers to offer a secure base. Dallos and Vetere (2009, 2014) describes how concepts from attachment theory as secure base (Bowlby, 1988) may be applied in systemic approaches. To be this secure base in challenging situations when Gabriel is overwhelmed by anxiety and other difficult feelings, he needs Claire to remain "strong" and capable of accommodating and containing his anxiety. Through theoretical and practical training, systemic practitioners will be aware of the influence of context on people's life and their possibilities to effect changes (de Flon, 2019b). In the case of Gabriel and Claire, we see that the material conditions have a significant impact on their situation. Duncan et al. (2010) claim that as much as 40% of the impact/outcome of therapeutic process is determined by factors outside the therapy, in other words, by what happens in the course of people living their everyday lives. In this case, it was necessary for the systemic therapist to be an advocate on behalf of the family in order to foster better possibilities for Claire to focus on her role and position as a caregiver for Gabriel. Sundet (2009) suggests in his research that the alliance between the family and the therapist becomes strengthened by a therapist's efforts to help with practical or material matters. This could mean writing letters of recommendation to social service or other services, adopting an advocacy role in meetings or making direct contact with other parts of the family's helping system.



This requires that practitioners take a position that secures a broad view of the family's context including their basic living conditions and show a capacity and willingness to expand the arena for systemic intervention to also include the professional system.

## Parental Conflict Resolution as Systemic Intervention: Peter and His Parents

Peter is 15 years old and lives with his parents Johnny and June. Their municipal case-manager contacted the FGS and asked if we could have some sessions with June. In the first session, she told us that Peter was diagnosed with ASD and Attention Deficit Hyperactivity Disorder (ADHD) and that the family were experiencing severe challenges and that she would like us to talk with the whole family. We, therefore, decided to meet in their house and asked that both her husband and Peter would be at home. Peter said initially at the first session that it was not his first choice to start the day talking to a therapist but he could do it if we all could speak English in the session. His parents had already told me that he preferred English also at home with them and in school. Both his parents have other languages than Norwegian as their first languages, but they do not share the same first language. I said that was OK, but in my inner conversation with myself I was quite pessimistic about how I could perform as a family therapist in English. But I thought this was one way to try to build an alliance with Peter so I jumped into it. In my inner conversation, I also had Duncan (2014) in mind who maintains that therapists should be flexible in their work in order to achieve contact and build a working alliance with the client. One of the main characteristics of ASD is challenges with language (Reindal et al., 2023). I also knew that these challenges with language could be of many different kinds. Against this background as well I thought it was the right thing to follow his wish. In the session, it soon became clear that his parents often had opposite opinions about almost everything and that their communication was characterized by a mutual specification of each other in negative ways and by raised voices against each other. This obviously bothered Peter, and after a while he left the table where we

were seated and moved down onto the floor and found a place to sit by his cat that had been sleeping in the corner of the room. He started to comfort the cat, and the cat seemed to like it. I then asked him what he thought about the conversation so far and what he thought would be helpful for the family. He then said; “both the cat and I would have a better life if the two of them (pointing to the parents) could stop arguing and treating each other like crap.” This was a powerful statement and the parents stopped arguing and looked rather sad and surprised. I used the moment to ask them how they felt about what Peter just said. Johnny said that he was not aware of the strength of his son’s feelings about how he and his wife communicated. “He is always in his room gaming on his computer, and I really did not know that he had heard so much of our arguing.” June said that she knew very well and thought it was very strange that Johnny did not know. Johnny reacted to this and soon their arguing was speeding up again. “Now you can see for yourself” Peter said. “They cannot stop, and it is really bothering me a lot because they are arguing almost always about me – it is not cool to be reminded that I am such a burden to them.” Both parents said to him that he was not a burden, but I think he did not believe them. I then suggested that the next sessions should be without Peter to give the parents an opportunity to work on their relationship.

This case focused on the importance of the therapist’s ability to be flexible in their work with families with children that need extra care (Sheehan, 2020). The original request from this family was to help the family to communicate better. When the parents showed that they could not hold their conflict away from Peter, and he told the therapist very clearly that he was much bothered by the way they treated each other, it was important for the therapist to be flexible enough to change the focus from finding the right language in which the whole family could communicate and engage with him to assisting the parents with conflict resolution techniques to be applied to the area of their parenting of Peter.

## Harnessing Family Resources: Taylor, Her Mother and Extended Family

Taylor is a 9-year-old girl who has been through several brain surgeries because of a severe epileptic condition. Assessment has shown that her cognitive function is that of a 5-year-old child. Managing her medication is challenging because her epilepsy is unstable and unpredictable. Her cognitive function is affected by the epilepsy and the medication. Assessment of her epilepsy has shown that she gets small seizures several times a day which are not always possible to recognize, even for her mother. The seizures can be observed as small periods of “vanishing.”

Early in the contact with the family Taylor’s mother spoke about her struggle to convince her family about Taylor’s condition. She said that she experienced them as having various ways of overlooking her challenges and expecting too much of her. This could often lead to difficult situations where, for example, one of Taylor’s aunts or her grandfather, made too excessive demands or expectations of her. This often led to conflict between Taylor and her relatives which greatly concerned Andrea, Taylor’s mother. Lately, Taylor was refusing to be looked after by anyone other than her mother. Andrea really needed the respite her relatives could offer, but in the current situation they were not in a position to be the resources she desperately needed.

A systemic therapist working with families with children needing extra care and with challenges that in some ways will remain has to be able to work in many ways and on many different levels (de Flon, 2019a) In this situation, the therapist suggested convening the family, inspired by the concept of family conference groups (Frost et al., 2014). The intention with this intervention is to harness the family resources in order to move towards a more unified understanding of Taylor and her needs. In the gathering Andrea, her sister and her partner and 3 grandparents participated. The therapist proceeded by speaking about the intention for the meeting and gave a summary of Taylor’s condition based on the assessment and the consequences for her and her functioning. This “teaching” or psychoeducation of the family is a way of creating a common base for exchange of experiences and knowledge about Taylor. This “teaching” was followed up with an interview with

Andrea about Taylor and what she as her mother needed from the family while the other family members were listening. The conversation was organized as a kind of reflecting team (Andersen, 1991; de Flon, 2017), giving the family opportunity to comment on what they had heard. In the following conversation, the family expressed surprise at hearing about Taylor's cognitive level and how the epilepsy affects her behaviour. This knowledge and Andrea's expression of her needs connected to being a parent for Taylor triggered a conversation about how they could be helpful. This led to a better situation for Taylor and Andrea and the family started a process becoming more like a team trying to achieve the same goals.

## The Therapeutic Relationship and Its Support

Building and maintaining the therapeutic relationship with parents and children in families 'where challenges remain' poses many of its own challenges for systemic therapists no matter how experienced such practitioners might be. It often means entering a relational field where parents already feel let down by, and distrustful of, outside services who they feel do not comprehend the magnitude of the daily tasks they face in caring for their child. Indeed, when coming face-to-face with the enormity of demands falling naturally on the parents of children with very serious and unremitting physical and psychological conditions, the first reaction experienced by the practitioner may be a desire to run in the opposite direction as fast as they can. While wanting to build trust with parents and children, they may be met initially by a very hesitant parental response allied to a cynicism regarding the meaningfulness of a professional presence in their lives.

The systemic practitioner needs to have patience with the trust building process which may only progress through repeated engagement and often enduring together repeated failure in the shared efforts to bring about some degree of amelioration in the family's situation. The irony is that client trust in the therapist may only evolve out of an experience of the professional's authentic efforts to assist and to go on trying to assist in contexts where a pattern of 'one step forward followed

by two steps backwards' seems to be the norm. There is something about the process of the professional's exposure to the intensity of child demands upon parents and their daily confrontation with unsolvable problems that builds a unique form of professional-parent solidarity over time. Alongside patience, the systemic practitioner needs the capacity to witness the prolonged and enduring suffering of both parents and children. Witnessing always involves a capacity to *listen* carefully to the experiences of parents but also involves a willingness to *see* first-hand some of the different predictable daily crises that the care of their children presents. An empathic kind of witnessing involves engaging as deeply as one can with the enduring suffering of parents before returning to oneself with the realization that 'this could have been me'.

The therapeutic relationship in families where challenges remain also requires a flexibility on the part of the practitioner. While many therapeutic meetings may happen in the professional's office while the child is either at school or being cared for elsewhere, the relationship will often require that some meetings happen in the family home and some of these meetings may need to happen as part of a response to an unforeseen crisis which occurs outside of normal working hours. An adaptable, flexible positioning on the part of the systemic therapist is part of what assists with the continuous building of a trusting client-professional relationship where the clients experience the authentic, heart-filled and caring engagement of the practitioner.

Working with such parents and family situations can be very demanding for professionals. It is not unusual for practitioners to shrink back from situations when confronted with the enormity of what a parent and child may be experiencing. They may try to persuade their supervisor that the case should be closed as nothing can be achieved or they may come up with some reasons why the work should be passed on from themselves to another practitioner. Or they may feel assaulted within by intolerable feelings of guilt and abandonment as they leave behind a distressed parent and a screaming child on a Friday evening on the way to meet their own partner and children for a pizza on the same evening. While it is inevitable that some therapeutic relationships have to end for a myriad of different reasons, the needs of most families in

contexts where ‘the challenges remain’ are better fulfilled when their therapists also ‘remain’. However, for therapists to find the capacity to not only remain but remain in an active, engaged, empathic and dependable positioning in their relationship with families they need a level of support that does justice to the nature of their own challenge. This means having a regular, dependable and engaged relationship with a trusted supervisor who knows the territory of the practitioner’s work. It means having a supervisor who can ‘hold’ the practitioner as they grapple with the many complex emotions that may be aroused in the process of witnessing the intense suffering of others where such suffering is likely to find no real abatement other than small levels of transformation flowing from the experience of solidarity that joins the client family, the systemic therapist and their supervisor. It is also important for the practitioner or the therapist to be part of a supportive systems of colleagues to discuss, reflect and share joys and challenges connected to their work.

## Conclusion

The purpose of this chapter has been to demonstrate both the utility and complexity of the systemic practices that address the situation where families need support in contexts where they have children with chronic conditions who need extra care and where no end to the challenges comes into view. The chapter has highlighted just a small sample of the systemic skills deployed by practitioners in this service arena. Another aim in writing this chapter has been to give further recognition to this domain of systemic practice as a specialism in its own right. The complexity of the territory offers itself to either the novice or experienced practitioner as a ground rich with possibilities for personal and professional growth and development. At the centre of the work lies the therapeutic relationship where trust must often be built slowly and patiently through a series of trials, setbacks and provisional successes. The role of the supervisory relationship has also been characterized as a critical support for the many roles and functions performed by the practitioner.

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